# Alberta Brain Injury Network

# Survival Guide

**Additional copies of this guide are available from:**
Your local Alberta Brain Injury Network Office
(See Resources Section)

**Or**

Alberta Community Development
Community Support Systems Division
Brain Injury Message Line
Call Toll Free 310-0000 then dial 780-415-2747

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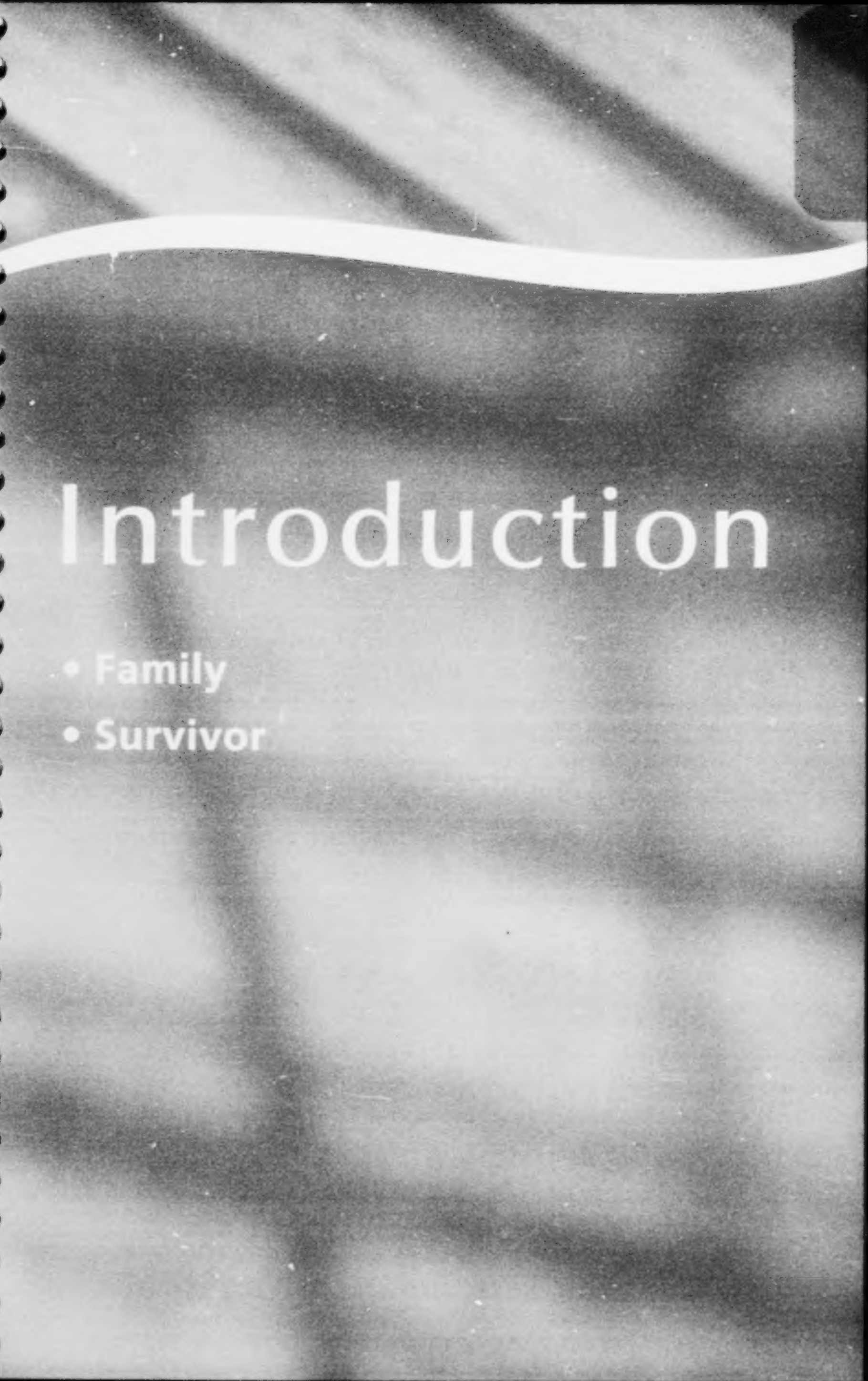

# Introduction

- Family
- Survivor

## Family

Dear Family, Friends, Advocates, and Caregivers,

Although much of this book is written with the survivor as the audience, it is certainly meant for you as well. We know that this is a difficult time for you, and you probably have many questions. We hope this book can be a starting point for you.

Although the parts in this booklet marked "Family Matters" will probably be of special interest to you, you will need to read the entire chapter in order to get all of the information you need.

## Survivor

Dear Survivor,

This book is to give information and support to you, the recipient of a brain injury. It is also to help your family, friends, advocates, and caregivers to understand more about your injury, and for you to understand more about what they are going through. Since each brain injury is different, not all of the information in this guide will apply to you. Alberta Community Development hopes that this book will help you on your journey towards a "new normal" after your injury.

This book is not meant to be a step-by-step guide to daily living with a brain injury. It is not meant to replace any information provided by the health professionals working with you and your family. This book offers general information on issues you may encounter following a brain injury and will try to give you practical advice for getting started towards finding your new normal. You may find that there is a new normal for every stage of the recovery. Some people find that after their injury, they need to re-adjust to a new normal every day. This book will also try to point you in the right direction to find the support and resources in Alberta that you need.

Recovery from brain injury is a long process. Great improvements may be seen in the first year, but progress may continue for many years. You and your family's adjustment is also a long process. We hope you will find some expression in this book of your own experience - that you will realize you are not alone and your responses to this sudden and major change in life are normal.

Brain injury survivors have reviewed all of the information in this book. All of the suggestions you find in this book are from people living with a brain injury who say these things work for them. The suggestions are from people who had to relearn simple tasks, who had to learn to live with severe vision problems, and who lost friends and family because of their brain injury. These people have figured out how to live with their new normal and are still learning. We hope you can learn from their suggestions and experiences.

The effects of a brain injury are as individual as you are. While this book will mention many possible effects that you could be suffering, you will need to see for yourself what is now normal for you.

There are no secrets to living successfully with a brain injury. You have to just keep trying and seeing what works for you. There are suggestions in this book, but they are only suggestions. If they do not work for you, try another suggestion, or invent something that does work for you. Your family, friends, and caregivers may have lot of suggestions that may be useful, but only you will know what works for you.

While this book is mostly targeted towards people with brain injuries, it is full of information that will be very useful for your family, friends, advocates, and caregivers. It will help them understand what you are going through. It will also be helpful for you to read the sections called "Family Matters". This is a difficult time for them too, and it will help you understand how they feel.

# NOTES

# 1

# Background on Brain Injury

- Acquired Brain Injury
- How Brain Damage Happens
- Parts of the Brain and How Injury Affects Them
- Severity of Brain Injury

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# CHAPTER 1

# Background on Brain Injury

**In this chapter, you will:**

- Read about Alberta's definition of Acquired Brain Injury and how that affects which supports you will be able to access.
- Learn about the different parts of the brain, and how damage to that part of the brain is likely to affect you.

### Survivor Matters

## Acquired Brain Injury

This book is for all survivors of a brain injury and their families. An Acquired Brain Injury means you hurt your brain sometime after you were born, not before. Also, the damage must be the result of an injury or an illness, but not an illness that gets worse with time, like Alzheimer's disease or multiple sclerosis.

In Alberta, if you injure your brain when you are younger than 18 years old, you may be able to get supports through PDD (Persons With Developmental Disabilities). Call 310-0000 to ask for the number of the PDD office nearest you. If your brain injury occurred when you were 18 years old or older, you are not eligible for supports from PDD, but we hope that this manual will help you find the supports you need.

Examples of Acquired Brain Injury include:

- traumatic brain injury, like a blow to the head or hitting one's head;
- brain tumours;
- brain infections, like meningitis and encephalitis;
- lack of oxygen, like what happens when someone almost drowns;
- strokes;
- violent shaking, as in Shaken Baby Syndrome or some whiplash injuries.

## How Brain Damage Happens

Brain damage results from changes to the brain caused by the injury or illness. Each injury or illness acts in different ways. Some common ways in which the brain is damaged include:

- bruising;
- bleeding (also called a hematoma);
- brain swelling;
- fever;
- lack of blood or oxygen to the brain (also called hypoxia and anoxia);
- shearing or tearing of brain cells when the brain is rapidly moved back and forth or twisted around (also called Diffuse Axonal Injury);
- pressure inside the skull (called increased intracranial pressure);
- objects taking up space in the brain (like tumours).

An acquired brain injury can lead to either local or diffuse damage. **Local damage** happens when only one or a few parts of the brain are hurt. If you are injured in this way, you would usually only notice a few changes. **Diffuse damage** happens when many parts of the brain are injured. If you have this type of damage, you would usually find many changes.

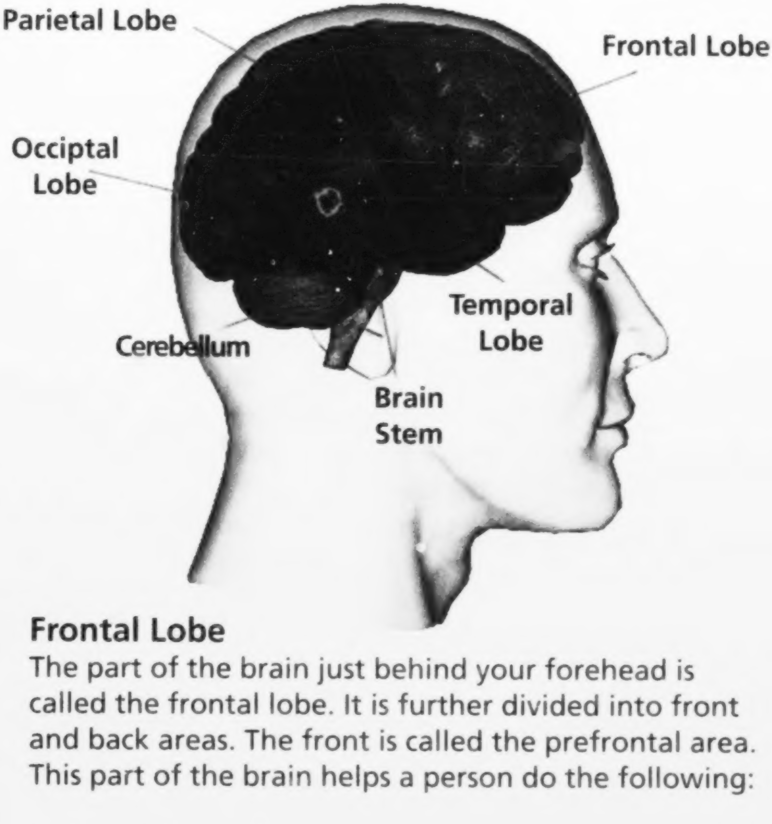
An example where either local or diffuse damage could occur is in a car crash. If a person's head hit the dash board and the brain hits the front of the skull it can be bruised or scraped. This damage is local because it happens only to the front of the brain.

A person can also have diffuse damage in a car crash. The brain is made up of millions of tiny cells. These cells connect the different parts of the brain to each other, but they are not very strong. In a crash where the brain moves rapidly back and forth, these brain cells are stretched and torn. This leads to tiny points of damage throughout the brain. This is an example of Diffuse Axonal Injury.

## Parts of the Brain and How Injury Affects Them

Although we do not completely understand how the brain works, we know that different parts of the brain help you do different things. Below are descriptions of parts of the brain that are often talked about. These descriptions include where the part is, what it usually does, and what behaviours a person might see after it is damaged. Memory problems can occur with any type of brain injury.

## Brain Map


Parietal Lobe
Frontal Lobe
Occiptal Lobe
Temporal Lobe
Cerebellum
Brain Stem

### Frontal Lobe

The part of the brain just behind your forehead is called the frontal lobe. It is further divided into front and back areas. The front is called the prefrontal area. This part of the brain helps a person do the following:

- plan and organize;
- solve problems;
- pay attention or shift attention;
- control impulses;
- get started on something;
- be aware of one's strengths and weaknesses;
- be aware of what others are thinking and feeling.

If you have an injury to this part of your brain, you might seem like a different person. You might appear more forward or rude than before. Your activity level might drop. You may even sit back and do nothing, unless told to. Many survivors may have more trouble paying attention or focusing than before the injury or illness. Others complain that they cannot get organized. Tasks like planning parties and even deciding what to wear can become a chore after this type of injury. In many cases, the survivor of a pre-frontal lobe injury may not be aware of the changes they have gone through, or they may not realize how others are affected by these changes.

The back area of the frontal lobe includes the precentral and the premotor areas. They help to plan the movements of the body. Damage to this part of the brain leads to problems starting and coordinating movements of arms, legs, and other body parts. Things like opening or closing your hands can take a lot of thought and effort after this kind of damage.

## Temporal Lobes

Your temporal lobes are located along the sides of your head above your ears. This part of the brain helps you:

- understand things you hear;
- remember things you see and hear;
- feel emotion.

Your right temporal lobe helps you understand and remember visual things like pictures and faces, and identify sounds. Your left temporal lobe helps you to understand and remember words, talk, and do math. Both lobes help you feel emotion. If you have damage to this part of the brain you may be unable to speak, understand others, read, recognize faces, or do math. You may have memory problems. You might also have trouble controlling your emotions, especially anger.

## Parietal Lobe

Behind your frontal lobe and between your temporal lobes is the parietal lobe. It is at the top of your head. This lobe is where information from sight, hearing, and touch are brought together. This area helps you:

- recognize how something feels (hard or soft, rough or smooth);
- know where your body parts are (my hand is on my lap);
- know where you are;
- coordinate seeing and moving (for example, hand-eye coordination);
- draw;
- read, write, and do math problems.

if you have damage to this lobe you might get lost easily, or you might have trouble reaching for things around you. You might not recognize your spouse's face, you may be unable to read a map, or draw a simple shape. You may also have problems with speaking, writing, reading, and doing math.

## Occipital Lobe

Behind the parietal lobe, at the back of your brain, is the occipital lobe. This part of your brain helps you to understand things that your eyes see. Problems with blindness and recognizing everyday things, like a toaster or a lamp, result from damage to this lobe. If you have damage to this lobe, you may have trouble naming colors, shapes, and other things you see. You may also have blind spots; however, all of these problems are rare.

### Cerebellum

Your cerebellum is at the very back and bottom of your brain. This part of your brain helps to make the movements of your body smooth and coordinated. Damage here can lead to poor balance, jerky movements, and shrinking muscles. This can make many everyday activities like walking, talking, and eating, difficult.

### Brain Stem

The brain stem is where the brain connects to the spinal cord. This part of your brain controls "involuntary functions" of your body, like your breathing and heart rate. It also controls how awake or sleepy you are. All of the nerve fibres that connect the different parts of your body to your brain travel through your brain stem. If you have a brain stem injury, you usually have trouble moving some part of your body. You may have an unusual walk or have to use a wheelchair. Your speech may be a little slurred or you may not be able to talk at all.

## Severity of Brain Injury

When someone is injured, everyone wants to know, "how bad is it?" and, "will you be normal again?" It is difficult to answer these questions. This is because there is no way to perfectly predict how much a person will recover. Health professionals sometimes use the severity of the injury as an indicator of prognosis. Prognosis is a medical term meaning how well you will recover. With traumatic brain injuries, the terms "mild," "moderate", and "severe" are used to judge prognosis.

For traumatic brain injuries resulting in a coma, the judgment of severity is based on the Glasgow Coma Scale (GCS) stages of emerging from a coma. The score is based on your ability to talk, to do what you are told, and to make eye contact.

Another measure of severity is your ability to learn new information. After an injury, people often cannot remember what has just happened. They do not know that they are in hospital or what day it is. This inability to remember is called post-traumatic amnesia or, for short, PTA. The severity is based on how long your PTA lasts after the injury.

Severity of injury is not always a good predictor of recovery and can vary greatly between individuals. The usual rule is the more severe the injury, the less likely you will return to normal. After a mild injury, 90 percent of individuals will be back to normal in a couple of days. Most survivors of a very severe injury will never regain all of their lost skills. Only a small portion of them will return to work or successfully complete school.

Someone with a mild brain injury might not even be admitted to the hospital. Most frequently, a mild injury is the result of a hit on the head caused by a fall or sudden violent motion, such as a car crash. At the time of the injury you may have one or more of the following symptoms:

- brief loss of consciousness;
- loss of the memories from immediately before, during, or after the injury;
- dizziness or clouded thinking at the time of the injury.

Symptoms of a mild brain injury often go away completely over a period of a couple of days to three months. Recovery is considered complete if symptoms do not stop you from doing your daily activities.

If you think you have had a mild brain injury, it is important to see a health professional who is experienced in treating brain injury. Health care professionals without this experience may brush the injury off because it is mild. Also, medical tests often do not show damage to the brain if time passes between the injury and the medical test. This means you might have a brain injury even if your medical test says you are normal. A professional who knows about brain injury can give information and encouragement to help you as you recover.

Brain injuries can lead to a number of problems. The most common symptoms include:

- poorer problem solving skills;
- language problems;
- personality changes and bursts of emotion;
- physical problems (poor balance, problems with vision, headache, fatigue, and physical disabilities, such as problems walking, sitting, etc.);
- problems in everyday living (poor memory and

attention, difficulties planning and setting goals, slowed thinking, and problems understanding others or speaking clearly);
- problems with emotional control (problems controlling one's temper, shifting emotions, lack of emotion, and increased anxiety);
- problems with motivation and self-control (poor hygiene, low sexual drive, lack of initiation, impulse buying, aggression, and saying inappropriate things);
- social problems (difficulty making or keeping friends, poor judgment in groups, standing too close to others, saying the wrong thing, and not understanding when people are tired, angry or bored).

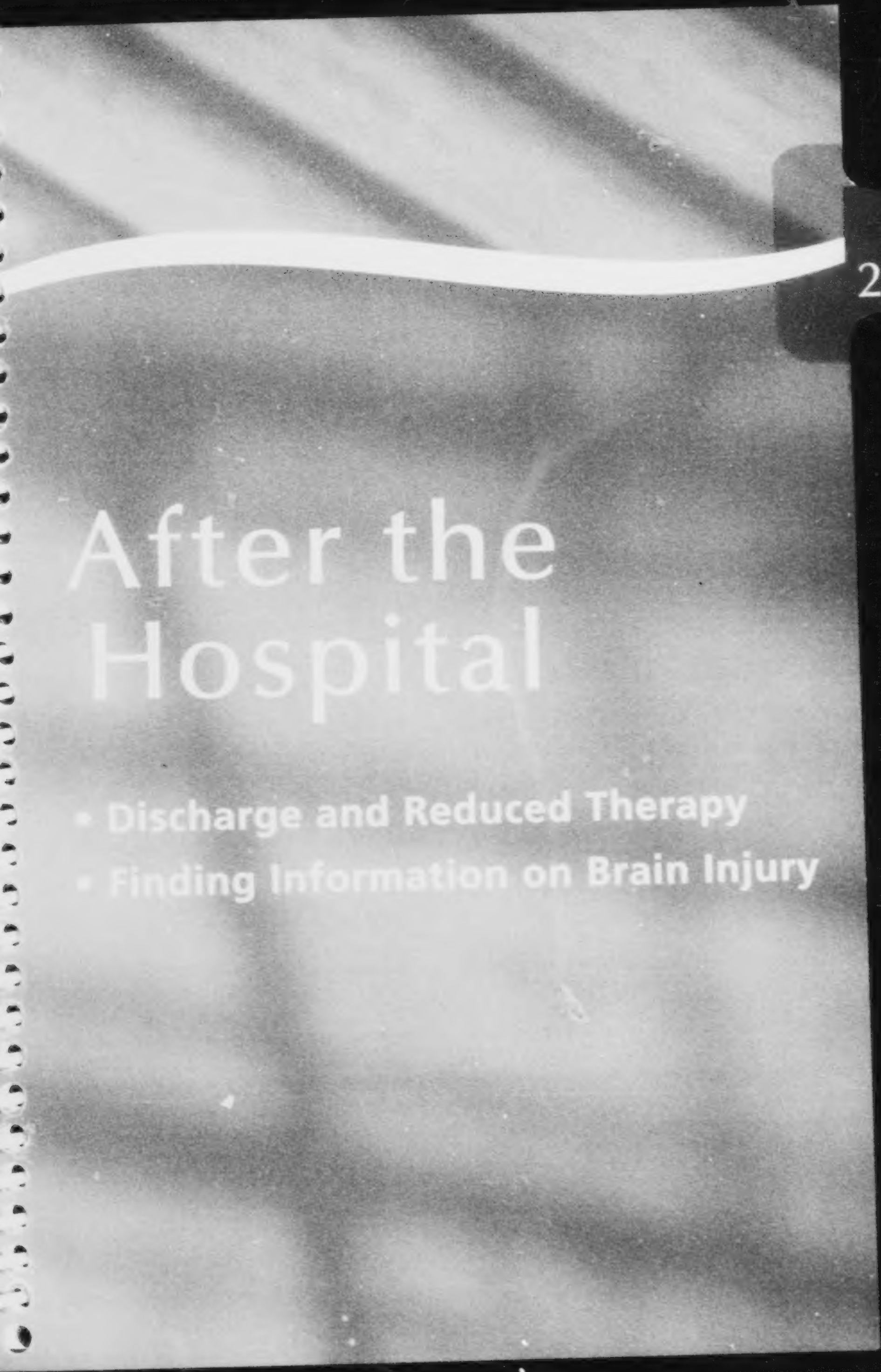
Changes after a brain injury can interfere with life. Some brain injury survivors will not successfully return to home, work, or school and may need ongoing support. Recovery from a brain injury may take months or it may take years. Some changes may be permanent.

## Measures of Severity

Knowing that an injury is mild, moderate, or severe tells us how bad things may be but this is not a perfect measure. Each injury is different, and each survivor is affected differently. There are stories of people so severely injured that they were near death but who recovered and went on to university. There are also stories of people with much less severe injuries whose lives have fallen apart. Measures of severity are, at best, a guide. It is how you are doing now and the improvements that you are making that tell best where you are going.

# NOTES

# NOTES



2

# After the Hospital

- Discharge and Reduced Therapy
- Finding Information on Brain Injury

## CHAPTER 2

# After the Hospital

In this chapter, you will:

- Learn the reasons for discharge and/or decrease in medical or therapy services.

- Learn how to find resources and information on brain injury.

**Survivor Matters**

## Discharge and Reduced Therapy

### Questions about Discharge

When you are discharged, you may wonder why you have to leave the hospital. This is a common concern and reflects people's fears about having to face how their lives have been changed by the injury. This may also be difficult for your family who may be worried about having to take care of you. These fears are often greatest when the injury has been severe, causing clear changes in your ability to think, get around, take care of yourself, and manage your feelings and behaviours. In these situations, the move out of the hospital is another major life change. Like many others, you may have questioned discharge because you still had many needs and you felt the move out of hospital or rehabilitation was too quick.

One answer is that maybe you gained what you could from your hospital or rehab stay, and needed to move on to make further improvements. Discharge from the hospital usually happens once you are medically stable; discharge from a rehabilitation ward occurs when your treatment goals have been achieved, or when the rehabilitation centre does not have the capability or resources to help you continue with your treatment goals.

Finally, you may have been discharged without being sent to a rehabilitation ward at all. That may be because you are not yet ready for the intense level of treatment offered. Those who are not ready may be sent to a long-term care centre or back home. To you, this may feel like your needs are being ignored. Remember, some individuals experience a slower recovery, but do improve to the point where they are ready for more intense treatment. It may take months or even years. When ready, you can begin treatment at the rehabilitation ward.

Returning home has benefits over staying in hospital. You may discover strengths and weaknesses at home, school or work that would not be seen in the hospital or rehabilitation ward. These strengths and weaknesses can be brought to the attention of health professionals. Finally, going home is a chance for independence that is hard to achieve in a hospital or rehabilitation ward.

## Dealing with Discharge

You can ease the stress of discharge by taking the following basic steps:

1. Ask the hospital staff if there is a discharge planner who can assist you with your discharge.

2. Get an advocate. An advocate is someone who will help you with some of the skills you have lost. They may help you organize your papers, take care of your finances, or help you get the supports you need. Choose someone who is good at the skills they will be helping you with. Choose someone who works well with you. If you have many needs, you may want to choose several advocates so that it is not too much work for one person.

3. Get organized. This is something an advocate can help you with. You may have lost your organizational skills or your motivizational skills. You may find that you are just not well enough or too tired to deal with organizing your papers. You should start a binder or folder containing reports, handouts, notes from meetings and lists of names and phone numbers. Include anything that forms a record of your care and could be used to help you or your family members to better understand the injury and its effects. This information will also be useful if you need to give detailed information to your lawyer or rehabilitation centre.

4. When a problem arises, get in touch with someone who has provided care in the past. This could be your family doctor or a specialist, your lawyer, or a rehabilitation worker. It is often not until you return home or go back to school or work that you notice problems. This is the time to contact professionals who can help you meet new challenges.

## Questions about Therapy

You may also feel your therapy is being limited. This concern usually arises when outpatient or community therapy, often provided by an occupational therapist, physiotherapist, social worker, speech-language pathologist or recreation therapist, is reduced.

Many therapists believe that life is the best therapy. Healthy people need to take care of themselves, get regular exercise, and find interesting things to do. Instead of visiting a therapist, the experience of living motivates them; that is, life provides exercise, stimulation, and training. Life should provide similar benefits for you.

Even if you may always need someone to assist you in living, that person does not need to be a therapist. A family member, friend, home health aide, or community worker could assist you. You are your own best advocate because only you know your life goals, but you may need a group of people to help direct you. It is important to have people around who can encourage you to do the things you need to do.

Independence is another reason to move on. Therapists believe that limiting the length of therapy can help you maintain your independence. If you rely on a therapist to keep fit and active, you are not being given the chance to take care of yourself. Feeling responsible for your own life can be a powerful feeling. People who have been given greater control over dressing themselves, feeding themselves, and doing everyday chores have shown amazing improvements in mood, conduct, and feelings of self-worth.

## The Impact of Limited Resources

The final part of the explanation for discharge and/or reduced therapy is that there is limited service available;

there may not be enough beds, or people to provide services. In rural or northern Alberta or in small communities, limits on available services may be the reason for discharge and/or reduced therapy.

In cases of discharge or reduced therapy due to limited resources, you will need an advocate to help you get better services. They may be able to help you adapt available resources to meet your needs. Go to your health board, band, political representative, your local Alberta Brain Injury Network office (see Resources), or your local brain injury association (see Resources) and ask how to get better services.

## Finding Information on Brain Injury

Another frequent concern for survivors and their family members is finding information on brain injury. This is not to say that nurses, doctors, social workers, and therapy staff have not done enough teaching. They have likely given you information about diagnosis (the name given to your type of brain injury); prognosis (how you are likely to do after you leave hospital); continuing therapy in the home; keeping safe and well; dealing with future difficulties; and making arrangements for services in the community. For several reasons, you may still want to know more. For instance:

- There always seems to be more to learn. As you and your family face new challenges, the need for more information may grow.

- Information provided in meetings with hospital staff or community workers may not "sink in." You may have been too tired or emotional to fully understand or remember it, or you may have memory or comprehension difficulties that prevent you from retaining it.

- You may want the "big picture", meaning you want more in-depth information on brain injury, its usual course, common and not-so-common problems, changes you might expect in your family, how to return to school or work, how to begin volunteering, how to work within the health care system or other organizations, and so on. This type of information is usually provided a little at a time, usually when there is a specific problem or issue to deal with.

- Finally, there are times when the information you want just is not made available. This usually occurs when your stay in hospital is short, due to a less severe injury and quicker physical recovery.

## Finding More Information

The solution to feeling uninformed is to gather as much information as possible. There are books, manuals, pamphlets, and videos your whole family can use. You can begin your search in the following places:

- Contact the local brain injury association nearest to you. See the Resources chapter for contact numbers.

- Search the Internet. The Resources chapter has several suggested sites to help you get started.

- Talk to local community therapists, staff at the hospital where you were treated, or volunteers or workers with health agencies and/or groups.

- Talk with other survivors and families of survivors who have gone through similar experiences. You may find their stories helpful and inspiring.
- Contact your local Alberta Brain Injury Network office. See the Resources chapter for contact numbers.

In your discussions with others, do not be afraid to ask to have things repeated or explained more than once. The information may have been provided in the hospital or by a community worker, and it may have been repeated several times already - none of that matters. What matters is that you understand the information. Always feel free to ask to have information repeated or written down. You could also ask people to say things in a way you understand. A good way to remember important information is to bring a tape recorder to record the meeting, or an advocate who will take notes for you.

# NOTES

3

# Ongoing Physical Problems

- Fatigue
- Headaches
- Dizziness

# CHAPTER 3

# Ongoing Physical Problems

**In this chapter, you will:**

- Find out some good techniques for coping with ongoing physical problems like fatigue, headaches, and dizziness.

### Survivor Matters

## Fatigue

The material in this section is condensed and adapted from Managing Fatigue: a Six Week Course for Energy Conservation.

Fatigue is a common problem among survivors of brain injury. You may not have the energy to do the things you used to do. This energy shortage or fatigue may be a temporary or a life-long problem. This section discusses basic concepts that will help you make the most of your energy.

### What to Expect

It is likely, especially soon after discharge from the hospital, that you will not be able to do all the things you did before the brain injury. You may experience fatigue in physical or mental ways. For example, you may:

- feel as if your whole body is worn out, or just certain parts are tired;

- find it difficult to concentrate or do other activities that involve thinking, focusing, remembering, or multi-tasking (all tiring activities for survivors of brain injury);

- become "grumpy" or "short" with others;

- say you are tired, lack energy, or lack the desire to do anything;

- become frustrated and feel "down" because your overall activity level is reduced;

- become distressed that you cannot do the things you used to do.

Stress from feeling frustrated or down can also increase fatigue. This creates a cycle of fatigue causing stress, which then increases fatigue. Understanding that you are operating at a different speed will help everyone– yourself, family members, and friends adjust their expectations.

## Managing Energy

To stop the cycle of fatigue or prevent it from happening, you need to manage your energy. This involves developing an energy "budget," saving as much energy as possible, and spending energy on meaningful and important things first.

To budget energy, you may need help with setting priorities, evaluating standards, and playing an active role in decision making.

- Setting priorities means deciding what activities are most important, and organizing the daily routine to accomplish these activities.

- Standards are expectations of the performance of an activity, such as how often something is done or how well it is done. Changing standards can free up energy and allow you to do things you really want to do. As part of the re-evaluation, you may gradually stop doing certain things.

- Playing an active role in decision making about how you will spend your energy will give you more control over your life. It might be helpful to make a list of activities and then decide what you will do, what you will not do, and what you might do if you have the energy.

## Learning to Rest

Resting is one of the best ways to save energy. Since it is important to rest before becoming fatigued, alternate rest and activity periods. This is called pacing. By alternating a tiring activity with a rest period, you will accomplish more.

There are many ways to rest: sitting, lying down, spending time in a quiet environment without distractions, listening to music, sleeping, or engaging in a quiet hobby. You will need to experiment with what type of rest works best, and when, how long, and how often you need to rest.

## Using a Daily Schedule

A daily schedule can be a big help in budgeting, saving, and spending energy. To create a daily schedule, start by inserting rest times through the day, then schedule activities around the rest times. Schedule the more difficult activities for times you are likely to have more energy, such as after a rest. You will spend less energy if your day is planned so that tasks requiring mental activity (concentration, thinking, problem-solving) are broken into shorter periods of time. A daily schedule not only provides a routine for the day, it functions as a memory aid and gives you a sense of control and accomplishment.

## Headaches

Headaches are quite prevalent after a brain injury. Their severity usually decreases over time, although some survivors are bothered by headaches for the rest of their lives. For severe headaches, it may be important to see a neurologist. Some survivors say they have found relief through alternative methods, such as acupuncture and massage, or by consulting an orthodontist or a chiropractor.

Some common terms for different types of headaches are:

- Muscle tension headaches tend to start from the back of the head and move around the side or over the top to the forehead. They are often the result of stretched head and neck muscles, caused by the force of the head jerking rapidly forward and backward at the time of injury.

- Migraine headaches tend to occur in the front of the head. Some survivors may complain that their forehead or temples throb, they may be sensitive to light, feel nauseated or actually vomit. Migraines may be caused by damage done to small blood vessels in the brain at the time of injury.

- Some survivors report a very sharp, sudden pain in the head, but because the pain usually only lasts a short time, doctors may not treat this type of headache.

- Analgesic rebound headaches are actually caused by the use (usually overuse) of analgesics (painkillers) for headaches.

## Treatment Tips

Treatment for headaches varies. The first step is to give the doctor a good description of the headache. This will help the doctor determine the best way to treat it. In difficult cases, it may be necessary to see a neurologist for help in controlling the headaches.

For muscle tension headaches, the following may prove helpful:

- Physiotherapy treatment, including exercises as instructed by the therapist.

- Experimenting with different pillows, including pillows specially designed to better support your neck. Poor neck position while sleeping can increase headaches.

- Ensuring the prescription for your glasses is correct. Straining while reading or watching television can increase muscle tension.

- Reading or watching television for short periods of time only, since the effort of concentrating may increase tension.

- Massaging uncomfortable muscles.

- Asking your doctor or therapist to show you how to do exercises that will help you relax your neck and shoulders.

- Using hot or cold packs on your neck or head.

Migraine headaches can be very difficult to treat. Medications are frequently used, but it can take time to find the right medication. It is very important to take medications exactly as prescribed. If you have trouble with your memory, you may need an advocate to remember for you. You can also use an aid, such as a watch alarm set to go off at medication time.

The following suggestions may be helpful for migraine-type headaches:

- Take prescribed migraine medication and lie down in a dark, quiet room as soon as a headache starts. Bright lights and noise can make migraines worse.

- Wear dark sunglasses (very dark ones are best).

- Keep track of what you have eaten prior to a headache as some foods can trigger a migraine. Also, it may be helpful to note what you were doing and what the weather was like prior to the onset of a migraine. This may help you notice a pattern, and help you avoid things that may trigger a migraine.

Several general tips can help ease muscle tension and migraine headaches:

- Get adequate rest. Fatigue can often cause headaches.
- Practice deep breathing and relaxation exercises for 20-30 minutes per day. Many headaches are associated with stress, and these exercises are excellent for relieving stress. Ask a psychologist, nurse, physiotherapist, or occupational therapist to teach you these exercises.
- Avoid noisy environments and too much stimulation.
- Do not concentrate too long on one thing.
- Stop smoking.
- Stop drinking caffeine beverages or limit yourself to 3-4 cups per day.

If headaches are severe and difficult to treat, you can keep a headache journal. In the journal, rate the severity of headaches on a scale discussed with your doctor, such as 1 to 10, with "1" being a mild headache and "10" being the worst. Also, write in the journal what events happened before the headaches. If a pattern can be seen, steps can be taken to prevent headaches.

Some over-the-counter medication can have serious side effects, like liver damage, so be sure you do not take more than the recommended daily dose. If you are exceeding the daily dose or feel the daily dose is inadequate, talk to your doctor about other solutions. This assumes you are not exceeding the daily dose due to memory difficulties.

## Dizziness

Dizziness is another common symptom that tends to get better with time. It can be described as a feeling of imbalance, lightheadedness, drunkenness, blurriness, or a "turning" sensation. It can last for seconds or hours, and may be severe enough to make it difficult to climb, bend, or move around. It can also result in nausea and/or vomiting. Dizziness may result from injury to the inner ear, eyes, or neck, or it may be due to emotional distress caused by the injury, or by side effects of the medication you are on.

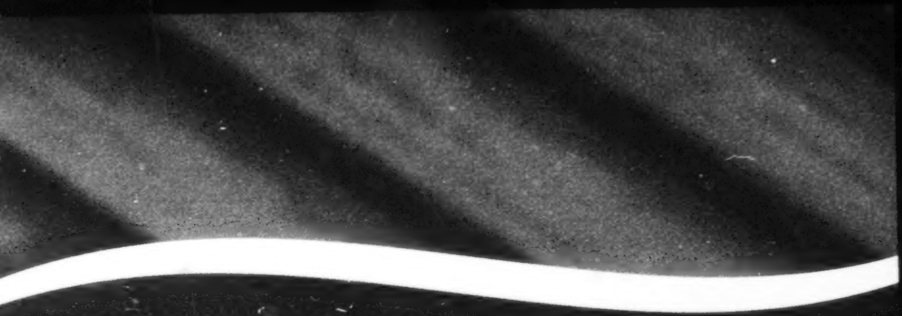
- Moving quickly can make dizziness worse. You can adapt by moving slowly, especially when changing from a lying to a standing position.

- If necessary, see an eye specialist, ear, nose and throat specialist, or physiotherapist for treatment. The specialist can help determine the exact cause of dizziness; the physiotherapist can provide exercises to help cope with dizziness.

- Be aware of what brings the dizziness on, and try to avoid those things. For example if you have difficulty taking elevators and escalators, use stairways instead.

# NOTES

# NOTES



4

# General Health

- Nutrition
- Medications
- Alcohol and Illegal Drugs

# CHAPTER 4

# General Health

**In this chapter, you will:**

- Learn how nutrition and general health can aid your recovery.
- Discover some tips on safe medication usage.
- Read how alcohol and illegal drugs can adversely affect your recovery.

### Survivor Matters

## Nutrition

Brain injury may change the way you relate to food. For some survivors memory problems may affect food intake. Damage to the brain can cause an inability to feel full or hungry, causing you to eat too much or too little without realizing it. You may have a changed or absent sense of taste or smell. This often happens in the earlier stages of recovery and may disappear as time goes on. This could also be a side effect of medication you are on.

The simplest way to manage many nutritional concerns is to create a meal plan and record what you are eating. This way, if you have problems remembering when you ate, or cannot tell when you feel full, you can refer to the record you are keeping.

### Canada's Food Guide

Canada's Food Guide to Healthy Eating provides basic information on good nutrition, encouraging you to enjoy a variety of foods. Canada's Food Guide to Healthy Eating identifies the four food groups and recommends the number of servings per day required by healthy Canadians. Factors such as age, weight, sex, activity, and medical concerns will influence how many servings are required from each of the four groups. Serving sizes can be adjusted to meet individual needs.

Emphasize cereals, breads, other grain products, vegetables, and fruit. Ensure that individual needs for energy, protein, and other nutrients are met. A nutritional assessment and follow-up by a dietitian may be required. Your doctor can probably recommend a dietitian for you to contact.

When choosing foods, take into account any problems you have with swallowing or food allergies. A speech-language pathologist can assess and treat swallowing problems; a dietitian can help with food allergies. Speech-language pathologists may be accessed through your Regional Health Authority or your local Alberta Brain Injury Network office (see Resources).

Choose low fat dairy products, lean meats, and food prepared with little or no fat.

If you are overweight, you may need to control portion sizes as well as fat content. If you are underweight or have increased energy requirements, you may need to provide higher fat foods to achieve and maintain a healthy weight.

You can also achieve and maintain a healthy body weight by participating in regular physical activity. Keep in mind that you may be restricted in what you can do because of poor balance, poor vision, fatigue, or other complications resulting from your brain injury. Keep looking for something that you are physically able to do, that you enjoy, and that contributes to your therapy. Physical, recreational, or occupational therapists may provide advice on the kinds of activities most suitable for you.

Limiting salt may help control high blood pressure and fluid retention if you have these concerns. Caffeine, which is found in coffee, tea, some colas, and chocolate, is a stimulant. Your ability to tolerate caffeine may be very limited, and it may be best to avoid all caffeine, especially in the initial stages of recovery. Even if the stimulating effect of caffeine is not a problem, Health Canada suggests having no more than four cups of brewed coffee (or the caffeine equivalent in other foods and beverages) per day.

Eating well is an important part of recovering from illness and maintaining good health. Follow Canada's Food Guide. If you are concerned about your nutritional needs, ask your health care team for a referral to an outpatient dietitian.

## Medications

Since taking more than one medication at a time can lead to drug interactions, it is important for the doctor writing the prescription and the pharmacist to know which drugs are being taken. If you have problems with memory, you can carry a list of your medications to show the doctor and the pharmacist, or you can have a friend or family member accompany you with the list. Go to the same pharmacy for all your prescriptions, and share the list with the pharmacist even when buying non-prescription or over-the-counter drugs, since interactions can occur with these as well.

## Follow Instructions

It is essential to follow instructions when taking medication. Drugs are most beneficial when taken in the right dose, at the right time, in the right way. Not following instructions may prevent the drug from doing its job and may cause serious side effects.

Pharmacists will usually give you an instruction sheet each time you fill a prescription. If they do not automatically give you one, ask for it. It will provide important information, such as common side effects and what you can do about them, drugs that should not be taken at the same time, and special instructions to ensure the drug is most effective, such as taking it between meals or with food. Take time to discuss any questions with your pharmacist.

## Memory Aids

If you have problems with your memory, there are several aids available that can help you take medication correctly. Purchase a dosette, a plastic container with separate pill compartments for different times of the day and different days of the week. Ask your pharmacy if they can put medications in individual bubble packages with labels showing the time and day pills in each package should be taken.

If you have serious memory impairment, you may need an advocate to remind you when it is time to take your medication.

## Commonly Used Medications

Since the changes that can occur from a brain injury vary widely, many different medications may be prescribed, based on necessity. This list of medications may include:

- **Anti-convulsants:** if you have seizures (convulsions) following the injury, you will probably be given a prescription for an anti-convulsant. The purpose of these drugs is to prevent seizures. The need for anti-convulsants will be re-evaluated by your physician on an ongoing basis. The drug may only be needed for a few months, but you should discuss the expected duration with your physician. Do not increase or decrease the dose without consulting your physician first.

- **Anti-depressants:** Some survivors and their caregivers experience depression. Depending on the level of depression, the physician may prescribe anti-depressants to help relieve feelings of sadness and hopelessness.

  Although originally used only to treat depression, this class of drugs is now proving useful in other situations as well. You may be given anti-depressants to help you have restorative sleep - the kind of sleep that makes you feel well-rested. They may be prescribed to help deal with certain types of pain, or they may be given to help decrease impulsiveness and emotionality, without causing the same side effects as other drugs.

- **Anti-spasmodics:** following brain injury, muscles in certain parts of the body may be tighter than usual. This may cause pain and altered use of the affected joints. Anti-spasmodic drugs help loosen muscles, which reduces pain and makes it easier to move joints properly.

- **Analgesics (painkillers):** you may experience some level of pain following a brain injury. Headaches and pain from tight muscles are two of the more common reasons for taking analgesics. Non-prescription painkillers, such as acetaminophen, are often useful for occasional pain relief. In more severe or chronic cases, a prescription medication may be required.

- **Psychotropics:** if you have problems with impulse control, meaning you do things without thinking about the consequences of your actions, you may be given psychotropic drugs. Acting without care for consequences can lead to embarrassing and even dangerous situations, and psychotropics may be helpful in controlling some impulsive behaviours.

## Alcohol And Illegal Drugs

Survivors of brain injury should abstain from alcohol consumption. This is extremely important in the initial stages of recovery. Alcohol affects the brain's ability to function. When the brain is already damaged, the effects of alcohol are more pronounced. Alcohol affects the brain in the following ways:

- limits recovery;

- increases problems with balance, walking, and talking;
- increases the likelihood of saying or doing things impulsively;
- interferes with the ability to think and learn new things;
- increases the chance of becoming depressed;
- increases the chance of having a seizure; and
- increases the chance of having another brain injury.

Consuming alcohol after a brain injury will likely increase complications. You may choose to ask your family or friends to help you by abstaining themselves.

If you were consuming alcohol to excess before the injury, additional help may be needed to change this destructive pattern. Find a health professional familiar with both alcohol abuse and brain injury to help you.

Most illegal drugs, such as marijuana and cocaine, hold the same dangers for survivors as alcohol. If you did not use illegal drugs before your injury, it is important to continue to abstain from use. If you did use illegal drugs before the injury, you may need the assistance of experienced drug counselors to stop. Continued drug use will put you at an extremely high risk of further brain injury.

# NOTES

# Rebuilding Skills

## 5

- Getting Help
- The Science of Rebuilding Skills
- Rebuilding Skills
- Conflicting Goals

# CHAPTER 5

# Rebuilding Skills

In this chapter, you will:

- Discover how you and your family view the changes that have occurred.
- Learn ways to avoid conflicts.
- Find out what tools you need to rebuild skills and learn how to work on them.

### Survivor Matters

## Getting Help

Everyone needs help at one time or another. After a brain injury, you and your family will probably need help. It can be hard to accept that you have lost some skills and independence after a brain injury. On the other hand, it is also hard for your family to accept that they may now have to take care of you, even though you used to be able to take care of yourself. Because this is such a difficult situation and there are so many issues to talk about, this chapter is divided into sections for you, the survivor, and sections for your family. However, we hope both you and your family will read both sections. This may help you begin to understand each other.

The question of helping is not always clear-cut. How much help should your family provide? How much help are you willing to accept? You and your family should consider these things:

### *Family Matters*

Prior to injury did the survivor tend to be independent or dependent, trusting or cautious, easy-going or difficult? How much has this changed since the injury?

______________________________________________

______________________________________________

Has their ability to think been affected? For example, do they have memory problems, has their thinking slowed down, do they show poor judgment?

______________________________________________

______________________________________________

After their stay in hospital, does the survivor expect others to cater to them? This can affect their willingness to do things for themselves.

______________________________________________

______________________________________________

## Survivor Matters

How do you feel about the changes in your life? Are you angry or depressed? Do you understand the changes?

______________________________________________

______________________________________________

Does your family expect you to follow their goals for your recovery instead of your own? Are they willing to give you the help you think you need? Does your family understand that their level of help might need to change from day to day, depending on how well you are doing on that day?

It is not surprising there are no simple answers to questions of how much help should or will be provided to you. The fact is, there is no "right" answer. The amount of help that should be provided depends on you and your family's circumstances.

## The Science of Rebuilding Skills

Since this is a difficult and emotional time for both you and your family it might be helpful to lay down some ground rules to encourage compromise and avoid conflict. The first suggestion is to approach helping like a scientist. Scientists always test their ideas; you can do the same while you are trying to rebuild skills. Testing is important because although you may feel like you are capable of doing the same things you could do before the accident, this might not be true. Testing is a safe way of assessing and improving your skills.

An added benefit of acting like a scientist is that helper and survivor can distance themselves from their emotions. Putting things to the test can lead to mutual co-operation between helper and survivor.

## Rules to Remember

When putting things to the test, remember the following three rules:

1. The test must be safe. A good rule is to start small. This will set you up for success. If you want to cook a full meal, consider starting with a breakfast of toast and cereal, or a lunch of grilled cheese sandwiches and soup. The results will give you and your family

immediate feedback on any problem areas. If the test is a success, try something a little more difficult. If not, set more achievable goals or keep practicing to improve skills.

*Family Matters*

2. Do not assist if you feel uncomfortable. If the survivor wants to do something you feel is too dangerous, simply say "no". Saying "no" gives them two important pieces of information. First, it lets them know what makes you uncomfortable, which helps them understand what to expect of you and others. Second, it helps them make safer decisions. Like many of us, the survivor may sometimes push too far. Your refusal can lead to negotiation and a safer test. Remember, it is always okay to speak your feelings and misgivings.

### Survivor Matters

Listen to your family if they are uncomfortable when you try something new. It may be true that you will succeed in this task, but it is important to keep a good relationship with your family by trying to understand their fears. You can discuss a solution that you will both be happy with, like, "If I can make grilled cheese sandwhich three times without any mistakes, then I will be given a chance to make a pasta supper by myself."

*Family Matters*

3. Natural consequences can be the best teachers. As a helper, it is important for you to allow natural consequences to follow actions, whether rewards or punishments. If the survivor waters the flowers, they enjoy credit for the beautiful blooms. If they burn the toast, they eat it burnt or throw it out and have to do it again.

The important point is that you do not bring on the rewards or punishments. When you let natural consequences occur, the survivor is less likely to blame you when things don't work out. It can also lead to fewer disagreements and an increased sense of self-control for the survivor.

## Rebuilding Skills

### Insight

Insight is a sense of one's own abilities. For example, knowing you can jump down three stairs, but not ten, is insight. The brain injury may affect your insight. Insight may be slightly less than it was, markedly less, or, as is the case of a small number of survivors, virtually gone. This is called lack of insight.

If you suffer from lack of insight, you may need help seeing the consequences of your actions. Regular and ongoing results of tests done with a helper can provide this. For example, you could put up a chart in the kitchen and add check marks each time you successfully make toast. This provides you with clear, objective feedback and can help make up for your own lack of insight.

### Initiation

Initiation is also necessary for people to rebuild their skills. Initiation is the drive that pushes us to do the things we want to do or feel we should do. Some survivors of brain injury lose their drive. They are less interested in doing things for themselves than before their injury. This is called lack of initiation.

### *Family Matters*

As a helper, you may often find yourself doing a lot more than you would like for the survivor. Or you may find the survivor does things around you, but not without you. Ask yourself, what needs to happen to get the survivor to do things for themselves. Here are some suggestions:

- Find something that motivates the survivor. Praise can be a very powerful reward. People are more likely to work at something if they know that others appreciate their effort. You should also offer bigger rewards for completing tasks that are more difficult or tasks that the survivor particularly dislikes.

- Use reminders around the survivor, such as lists or signs that say what to do next, or verbal cues from helpers. It is helpful to ask the survivor what kind of reminders would be most useful to them.

## Survivor Matters

- Don't be afraid to reward yourself for doing tasks that you dislike or find difficult. Encourage other people to reward you for accomplishments. For example you can ask a family member or a good friend if they will treat you to a movie after you finally accomplish that big task that you were having trouble with.

- Use the kind of reminders that you find most helpful. If you prefer a computerized daily planner over a list stuck to the fridge, then that is what you should use. Experiment with different types of reminders until you find the way that works best for you. Other people may have good suggestions, but only you know what works best for you.

## Motivation

Lack of initiation should not be confused with lack of motivation. People who lack motivation do not want to do what is asked of them. People who lack initiation want to do something, but will not do it without encouragement.

Learned helplessness is one kind of lack of motivation. It occurs when a person cannot or is not allowed to escape a situation that is hurtful or difficult. From this experience, they begin to believe they have no control over their world and so lose motivation to help themselves. Some health workers believe learned helplessness can occur during the stay in the hospital. Survivors who have learned helplessness may appear listless, depressed, and/or uninterested in things around them. If this is the case you may want to:

- Try to do things for yourself, even if it is difficult or something you are not good at. This will help you regain a sense of self-control and help you remember that you can make a difference in your own life.

- Think about goals or desires that you would enjoy working towards and that would help you feel as if you were regaining control over your own life.

- Try to overcome any negative reactions over your lack of motivation. If you focus on staying positive, it may help you become interested in trying new things.

## Conflicting Goals

The survivor has to want to rebuild their skills; this desire is not always present. You may want the survivor to do things to ease the burden of care, which can be very high, or health workers may recommend building certain skills. In both cases, the survivor may not want to do this. The result is that you become involved in a plan to build skills the survivor does not want.

Differences between you and the survivor may express themselves in two common ways: passive resistance, when they agree to work on a skill but do not practice it; and active resistance, when they argue or fight when you try to assist with the skill. Passive resistance is much more difficult to identify, but a key symptom is a feeling of dissatisfaction on the part of the helper. The reasons for your dissatisfaction will remain unclear until your differences are uncovered.

One way to reduce differences between you and the survivor is to involve them in planning the rebuilding of skills. Experience has taught health workers that a key to success is accepting the survivor's goals for treatment.

Accepting goals from the survivor may be even more important once they return home, but it may take extra effort. They may be unable or unwilling to argue with health workers or caregivers. They may withhold their true feelings to keep the peace or because they do not want to offend. They may resist the whole process of planning to work on skills, because they want to do it on their own or because they are upset by suggestions from others, such as how to behave appropriately. Such resistance may be alleviated by certain techniques, (outlined in the "Survivor Matters" section).

## Survivor Matters

- You may have different goals for yourself than your family or helper has for you. These differences in goals can cause conflict. In this situation it may be a good idea to have a third person (someone who is not a part of this conflict) help you and your family or helper talk about your goals, either separately or together. The third person can then bring both of you together to develop a new plan for building skills.

- You and the helper can write down the goals that are most important to you. Then, with discussion, a few goals can be chosen from each list with an agreement to try to work on them. This takes into consideration the needs of the family. Some of your goals must meet the needs of others.

## *Family Matters*

- How does your family want to continue providing support if the goals of the survivor differ from your own? This is usually more of an issue when caring for the survivor takes a lot of effort, and/or the survivor is resistant, lacking insight, or simply difficult.

- When differences produce increased strain and dissatisfaction in your family, consult a counselor, either as a couple or a family. Even if the survivor is unable to benefit from counseling, your family may. Counseling can help you explore your commitment to the survivor and your concerns about providing care.

- A local brain injury society may be able to help direct you to a support group. Several of these brain injury societies can be found in the Resources chapter.

The discussion of the burden of care brings up an important issue. Should family members be the ones helping the survivor relearn skills? Supervision, especially after a severe brain injury, can be 24-hours a day. This can create relationships that lack the usual give-and-take, or where contrasting roles, such as lover and caretaker, form emotional conflicts for both the helper and the survivor. In most cases, family members are the only ones available to help relearn skills. If community or financial resources are available, you may want to explore whether someone else can do this work. Someone from outside the family will not experience the same stress and strain and may be able to provide the necessary direction and supervision without the emotional turmoil. Success at finding such a person is usually limited, and the resource is often time-limited or places a heavy financial burden on the family.

# NOTES

# NOTES

# Family

6

- Adjusting to the Changes
- Changes in the Survivor
- Increased Responsibilities
- Changes in Roles
- Changes in Relationships
- Separation, Divorce and Placing the Survivor Outside The Home

# CHAPTER 6

# Family

**In this chapter, you will:**

- Read about how a brain injury in the family can cause changes in responsibilities, roles and relationships.

- Learn about the possible effects of all these changes, as well as some ways to cope with them.

### Survivor Matters

## Adjusting to the Changes

Good or bad, life experiences change our families. Marriage, divorce, birth, and death are some experiences that we may know well. Each brings new responsibilities, roles, relationships and feelings. The key to living with these changes is learning to adjust.

How well you and your family adjust depends on the experience and the impact on your family. Adjustment is easier when the experience:

- is something that you want (like having a baby);

- is short-lived (short-lived might mean weeks to months);

- leads to few changes in the home.

Adjustment is easier when your family:

- likes challenges and looks for change;
- has a positive outlook;
- has family and friends who are willing to help;
- accepts help;
- has few other problems (like alcohol abuse or unemployment).

Living with a brain injury takes a lot of adjustment. This is not to say that you and your family will have problems with adjustment. You may not. If you do, you should know that it is quite normal. You should also know that there are things that you can do to help yourself. Often, the first step is to try to understand the changes that have happened. Greater understanding usually leads to a sense of control. Feeling in control can reduce stress and help you to make better choices when dealing with the changes that come with a brain injury.

## Changes in the Survivor

Changes to the family usually begin with you, the survivor. This is because it is what you can and cannot do that determines how the family must respond. Not all changes are alike, however. Some make a big difference to the family, while others do not.

Below is a list of common changes. You and each member of your family should go through the list below and check off those that apply. This will help paint a picture of the changes that you see in yourself, and the changes that the family sees in you. Hopefully, this exercise will help each member of your family understand how everyone views the situation.

☐ Aggressive
☐ Angry and critical
☐ Attention problems
☐ Balance problems
☐ Double vision or wandering eye
☐ Easily distracted
☐ Emotional (anxious or depressed)
☐ Forgets appointments, etc.
☐ Headaches
☐ Immature
☐ Impulsive
☐ Judgment is poor (bad decisions)
☐ Lack of initiation (does not try things)
☐ Lacks insight (unaware of problems)
☐ Lost easily
☐ Misunderstands what is said
☐ Moods are up and down
☐ Movements uncoordinated
☐ Poor problem-solving
☐ Problems with reading or writing
☐ Says the wrong thing
☐ Sensitive to noise
☐ Sexual interest changed (more/less)
☐ Sleep problems
☐ Stands too close to others
☐ Swears/Verbally abusive
☐ Talks too much
☐ Tires easily
☐ Trouble making decisions
☐ Worries too much

## Increased Responsibilities

Now you have a clearer picture of how everyone views the changes that you have experienced. The next step is to look at how these changes have increased family responsibilities. Family responsibilities are chores or duties that are done around the home that keep it working smoothly. How much more your family has to do can be a measure of how big the change has been in your home.

*Family Matters*

### Shifting Responsibility

Sometimes the survivor is not able to do things that they did before. The family's work increases because the survivor's responsibilities shift to other family members. Here are some examples of shifting responsibilities:

- The survivor used to handle the money. Now they make a lot of errors when doing the math. As a result, you have to balance the cheque book.

- The survivor used to help with meals. Now they forget simple things like how much water to put in the rice. When they have problems like this they just do not cook. The result is that you end up cooking all the time.

- They used to watch the children when you went bowling. Now the survivor is losing their temper with the children all the time. You give up your bowling so that you can stay home and watch the children.

- The survivor used to take the kids to everything. Now the kids think the survivor says embarrassing things and they either go alone, or ask you to take them.

### New Responsibility

Some responsibilities may be totally new to your family. These are usually chores or duties the survivor did for themselves before the injury or illness. Things that you might already have found yourself doing for the survivor include:

- taking care of them, such as getting them dressed, bathed, or on the toilet;

- supervising the survivor;

- dealing with medical needs, such as giving medications or reminders about appointments;

- correcting the survivor or helping them to relearn skills;

- dealing with out of control emotions and behavior.

A helpful exercise might be to write a list of new responsibilities as you think of them.

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________________________________________

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________________________________________

### Survivor Matters

## Changes in Roles

Changing responsibilities lead to changing roles. Roles are made up of groups of chores that we do. For example, the role of homemaker includes cooking, cleaning, watching the kids, and so on. But there is more to a role. Being in a role means making decisions and taking authority. The homemaker not only does the cooking, but decides what to cook and when. They also direct others to do things, like set the table.

### *Family Matters*

Each member of the family might try making a list of the new roles that they and others have taken on. Do not forget to include how these new roles make you feel. For instance, roles bring work, but they also bring status. Status makes us feel better about ourselves. The family member who does more often gets more credit. This can lead to feelings of being valued and important.

## Survivor Matters

It may be the reverse for you. You may do less and feel like you are valued less. You might react to this in a number of ways:

- grief as you feel you are not needed;
- anger at not being valued (especially if you have poor insight);
- apathy because of your inability to change things around you;
- relief because you can let go of responsibilities.

Write down some of your feelings.

*Family Matters*
How the family feels about the survivor's loss of roles is also important. Many families feel guilty. This often happens when the survivor is unhappy with the changes. Other families struggle with the dilemma of how to include the survivor. If they make the decisions alone, they risk the survivor's anger. If they let the survivor decide, they might not be able to live with the decision. Both options can lead to feelings of frustration, anger, and resentment. Write down your feelings about this.

Finally, there is one change in role that spouses say is uniquely difficult; the shift from spouse to caregiver. A caregiver is a person that feeds, dresses, and otherwise cares for another person. It is a common role for parents of young children. Being a caregiver for a spouse is unusual and can be very unrewarding. Spouses need a give and take relationship in their marriage. Many do not get that when they are a caregiver.

Write down your feelings about this.

## Changes in Relationships

Three things change relationships after brain injury:

- shifting roles;

- changes in the survivor's personality; and

- less time spent with other family members.

Shifting roles change relationships between the survivor and family members. A child who watches over his father might not give him the same respect. A wife who cannot banter with her husband and turn to him for advice may not feel she has a partner.

Personality changes often alter how much you like the survivor. Likeable changes can strengthen the relationship, like when a gruff father becomes warmer and kinder. However, the changes can often lead to a less likeable person. At its worst, the survivor changes so much that they seem like another person. A wife described her experience as being widowed and married at the same time... and to someone she would never have had as a friend. A son said he could handle it if his dad had died, and he could handle having a strange man in the house, but that the strange man was in his dad's body was more than he could take.

Relationships between all family members can change when the survivor demands a lot of time. Time spent on the survivor means that others in the family need to do more for themselves. This can be good or bad. In families that have a child with a disability, about half of siblings become more mature. They care more for others, are more independent, and develop a strong sense of helping others. The other half become jealous and resentful. They say that they missed time with their parents. Couples with either a spouse or child survivor may also go either way. Some pull together and become stronger. Others fall apart entirely.

## Common Responses

Your reaction to the changing family is very important. How have you felt? What do you experience? What has been your and your family's reaction to the changes? Use the ideas below to help you think about how you have been dealing with your new family. Make a list of your thoughts, feelings, and reactions.

________________________________________

________________________________________

## Effects of Changing Responsibilities, Roles and Relationships

Most people see very quickly that things have changed greatly since the injury or illness. The family has much more to do now than before. You might have to expend much more effort on even the simplest tasks. What you might not notice right away is how your feelings have changed. If you feel the change has been particularly difficult and unrewarding you might:

- resent the unfairness of it;
- grow frustrated with the process of regaining skills;
- simmer or rage at others who do not understand;
- fear letting your family down, because you cannot do it any more;
- wish it never happened, or wish that you had died;
- feel that you have been returned to a role you thought you left behind. As an adult, you may fear being treated like a child for the rest of your life.

It is important to realize that these feelings are normal. They are part of adjusting to the new family situation.

It is easy to feel unappreciated. Many of the things you do can go unnoticed. Many of the difficulties you face are unseen by others. Brain injury has been called the invisible injury. It is its invisibility that often leads others to underestimate what you have to do to manage.

## Denial

No one wants to believe that they are in denial, but denial is common. It is a normal part of the healing process. When you do not deal with issues that must be dealt with, denial becomes a problem. This can mean that you or your family are ignoring a problem until it becomes dangerous; it can also lead to trying something that is unsafe.

Denial can be the result of a misconception. You may think, "If I have a brain injury I am useless to my family; so I cannot have a brain injury." Sometimes all you need to do is change the misconception in order to put denial behind you, "A brain injury means that I may have more difficulty in some tasks than I did before the injury, but that does not mean that I am not an essential part of my family."

## Depression

Another common difficulty after brain injury is depression. This may include feeling "down in the dumps" or even thoughts of suicide. These feelings are normal and nothing to feel ashamed of. A brain injury is a very unusual situation. It can take amazing strength to cope with it. Sometimes your ability to cope is simply overwhelmed.

It is important, however, to know if and when you need help. The following are signs that you may need to seek help from a professional counselor or doctor:

- Do you find yourself crying uncontrollably for no reason?
- Are you beginning to feel hopeless, like there is nothing you can do to make things better?
- Do you find that you have lost interest in things that you used to enjoy?
- Are you tired and listless?
- Are you having trouble getting to sleep or waking up early and unable to get back to sleep?
- Have you had a serious change in appetite?
- Are you having thoughts of hurting yourself or thoughts of suicide?

If you are experiencing any of these, especially thoughts of hurting yourself or suicide, you should see a counselor or doctor right away.

## Coping Ideas

Look over what you have learned about changes in your family. Look over what you have written in the last few pages and then ask yourself these questions:

- Has there been much change?
- Has that change led to good feelings, bad feelings,

or mixed feelings?

- In what parts of my family's life have I seen change?
- What changes have led to very strong feelings?

________________________________________________

________________________________________________

Below are some coping strategies that may help if the changes in your family have become a concern to you or any of the family members.

## What you found

Too many new responsibilities, or difficulty keeping up with tasks that were simple before the injury.

## Suggestions for coping

The key to coping here is to reduce demands on your time. You might try the following:

1. Simplify your life. Things are not going to pick up where they left off. Do not do anything you do not have to for awhile.

2. Find out if you can pay for help. Home Care, private companies, and live in nannies or housekeepers are some possibilities. You should check if the cost of this service will be paid by your insurance.

3. Pass some duties to a family member, advocate, or close friend. Try to spread out the duties between several people to keep everyone from feeling overburdened.

*4.Family Matters*

Pass some duties back to the survivor. Family members find themselves doing a lot for the survivor because they fear for the survivor's safety or dignity. Letting the survivor try things is the way to pass these duties back to them. Suggestions for how to do this can be found in chapter 5 called "Rebuilding Skills."

## What you found

New roles are overwhelming. A lot of stress in roles comes from being responsible. The idea here is to let go of your role for a while to take the weight off your shoulders.

## Suggestions for coping

Try the following:

1. Make time for fun or relaxation. It does not have to be a lot. It could be 15 minutes of listening to music, coffee with a friend, or an evening playing ball. The thing is to drop the load you are carrying for a little while and have fun.

2. Take one day at a time. When you feel overwhelmed, take one hour at a time.

*Family Matters*

## What you found

New roles are upsetting for the survivor or other family members.

## Suggestions for coping

You should acknowledge the survivor's feelings even if you cannot deal with the problem right away. When the family is ready to deal with the difficulty of new roles you might try the following:

1. The survivor and family should develop a plan together when making decisions about the recovery goals. Both the family and the survivor should list their worries and problems. You may want to limit the list to each family member's top three worries so that no one feels overwhelmed or attacked. The key is to avoid letting your worries build up until you explode at the other person. You may want to have a professional involved when you do the planning. This will help avoid a situation where one family member feels teamed up on.

2. Write down every family member's new roles. Make sure that everyone in the family has a role that makes them feel like an important member of the family. These roles should be defined and clearly understood by all family members. Keep in mind that these roles can and should change as the recovery process goes on. Again a professional might help here.

## What you found

The survivor is like a new person.

## Suggestions for coping

This is a unique experience. It is often best dealt with by talking to others who understand. You might try the following:

1. Go to a brain injury caregiver support group. Sharing your experience with others who know firsthand what you are going through can be helpful.

2. Talk to a counselor who knows about brain injury. Talking to someone knowledgeable about such changes can help you understand your feelings and help you make life decisions.

## Survivor Matters

### What you found

You or another family member appears depressed.

### Suggestions for coping

If a family member shows some serious signs of depression, you should see a professional. You can start with your family doctor. Your local brain injury association (see Resources) might be able to direct you to a private counselor or a support group.

### What you found

Denial is leading to difficulties in your home.

### Suggestions for coping

If it is your family who is in denial, they may be pushing you beyond your limits.

1. Talk about changes that you have noticed. This can be very effective, though sometimes the help of a professional is needed.

2. *"Family Matters"*
   If it is the survivor who is in denial, it may lead to them trying something unsafe. Help the survivor to see what they can and cannot do. (Use experiments to help them understand this concept.)

## What you found

You are unsatisfied as a caregiver.

## Suggestions for coping

This is likely the most uncomfortable issue to deal with. This is because this situation may lead to separation or divorce. The following are possibilities:

1. Try to make a change in your thinking. If your choice is to stay, it is helpful to find a way of thinking that helps you feel better. For example, some see caregiving as a Christian duty or an honorable way to spend one's life.

2. Find someone to talk to about your feelings. This could be a counselor, a friend, or a support group.

3. Look at other living arrangements. Sometimes the best choice for the family is to have the survivor live with someone else. For more information on your choices, read the "Housing" chapter.

## What you found

Some family members seem to be getting too little attention because most attention has been directed at the survivor.

## Suggestions for coping

The idea here is to see if you can make time for yourself and your family. You might try the following:

1. Set up regular activities just for those family members. It should be a special time for you and them. Some families have found that relatives, and family friends can also sometimes provide this quality time.

2. Explore respite services in your health district. Respite is discussed in the chapter called "Housing."

3. Plan a family getaway. This may include leaving the survivor with someone else.

4. Let the survivor get away for awhile. If the survivor has a close friend or family member that they can visit for a week or two, it can help ease everyone's tension.

One way to cope is to seek out a support group. Your local brain injury association will likely help form such groups. You can contact them to find out about one in your area (see Resources).

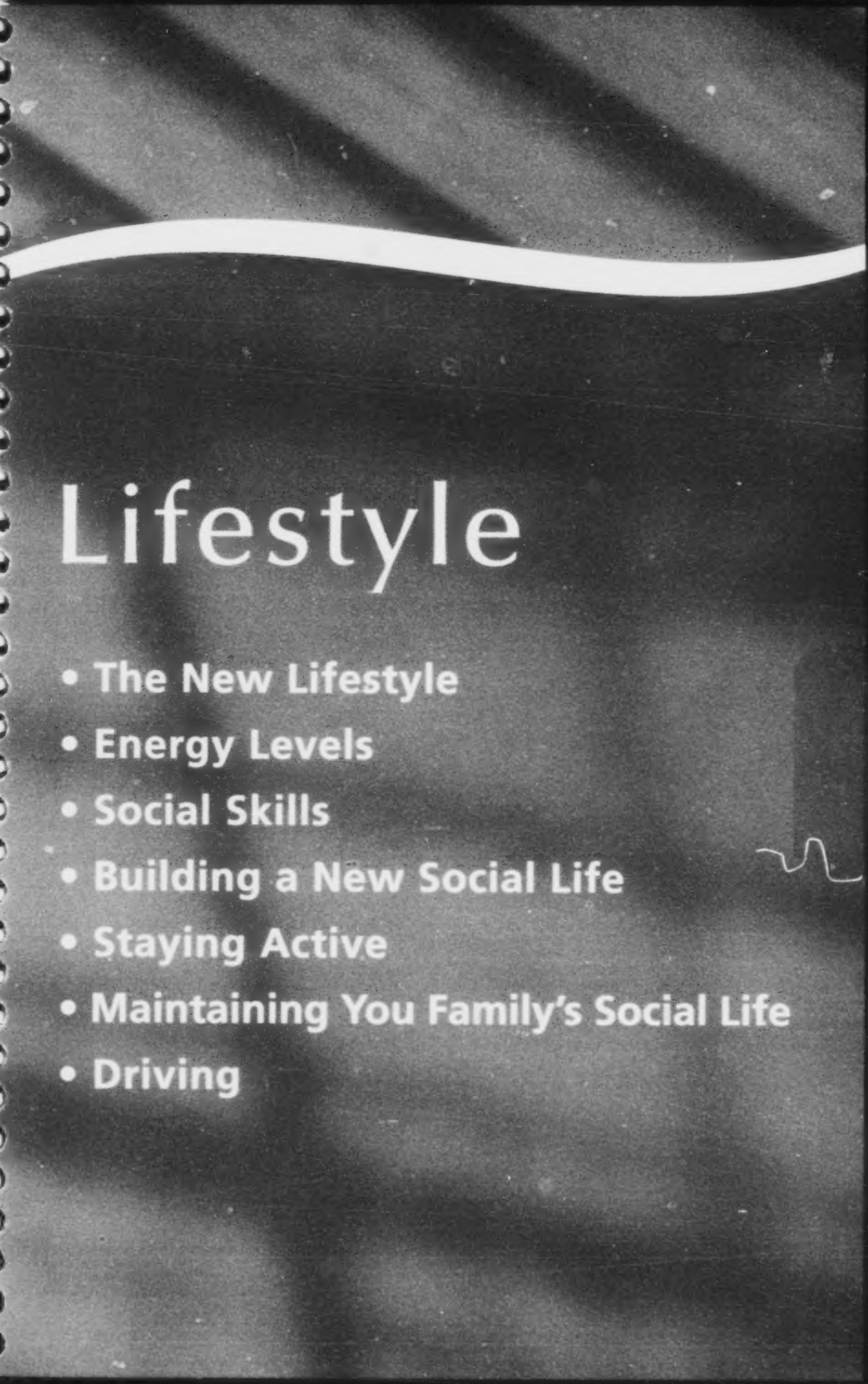
## Separation, Divorce, and Placing the Survivor Outside the Home

Leaving the survivor is a sensitive issue. Families have a lot of different feelings in these situations: guilt, because they feel they should continue to help the survivor or because they have wished the survivor dead; anger, because they feel health care professionals misled them into taking the survivor home or did not give them enough support after the survivor did return home; concern about how the choice to leave might affect the survivor and the rest of the family.

There is no universal answer to the question of whether the survivor should live at home or somewhere else. This is a sensitive issue and must be an individual choice for every family. It is a good idea to discuss this issue extensively with the survivor's doctor and other health care professionals, with a professional counselor, and with the survivor themselves before making any decisions.

# NOTES

# NOTES



# Lifestyle

- The New Lifestyle
- Energy Levels
- Social Skills
- Building a New Social Life
- Staying Active
- Maintaining You Family's Social Life
- Driving

# CHAPTER 7

# Lifestyle

**In this chapter, you will:**

- Learn about the importance of rebuilding your social life.
- Learn to adjust your social skills to accommodate changes.
- Read about when and how to have a driver evaluation done.

**Survivor Matters**

## The New Lifestyle

Each family responds to the changes brought by the brain injury in its own way and at its own pace. It can take a long time. It is also complicated because you cannot predict what abilities you will eventually have. Instead, you will be making adjustments throughout the different stages of recovery. One of the most helpful things you can do is allow yourself to grieve for the losses. As your grief is expressed, it will become easier to move forward and establish a new life.

### Energy Levels

In the beginning, you will not have the energy to maintain a busy lifestyle. While you may or may not regain your pre-injury level of activity, most people's overall energy level will gradually increase. 'Gradually' is the key word. It may seem that little is changing, but over the long term you will see a steady increase in your energy level. Fatigue will also be a factor for your family as their stress and responsibilities are greatly increased. Your whole family should consider simplifying its lifestyle. If your energy level does not gradually increase, consult your doctor.

## Social Skills

Social skills are essential to maintaining friendships, yet they may be affected by the brain injury. You may have difficulty with making eye contact, or you might dominate conversations, or say the same thing every time you see someone. You might stand or sit too close to others, or you may seem very rude. You might have difficulty showing emotion, causing your general expression to remain the same, whether hearing happy or sad news.

Other common behaviours that affect social skills include: impulsiveness, distractibility, inability to read subtle or non-verbal behaviour, and decreased sensitivity to other people's needs or social situations. You may have acceptable social skills but lack the memory or capacity for abstract thinking that is needed to participate in social activities.

If you have children, they may be most distressed by your lack of social skills. Pre-teens and early teens, in particular, are easily embarrassed by their parents at any time, and often find a parent who has difficulty with social skills very embarrassing. It may help children to tell friends about your injury and ignore strangers who stare, although this may be difficult to do.

It is important for your family to provide non-judgmental feedback about appropriate and inappropriate social behaviours. It may help to practice different social situations with your family, or a professional counselor or coach, to help you relearn appropriate behaviour. You may have to repeat these lessons if you have difficulty remembering or with applying learning from one situation to another. With repetition and coaching, many survivors regain their social skills.

### Building a New Social Life

When you first return home, a lot of energy will be spent adjusting to the new situation. At this point, it is important not to restrict your social life too much. This applies to everyone in the family. Because you may not have the physical energy or intellectual skills needed to maintain your previous social life, you may need to be creative in your efforts to build a new one. You could:

- Consult your family, or a friend you can trust, for direction in choosing safe social activities. If your judgment is impaired, it could lead you into unsafe situations. Your family's role is to encourage you to take risks, within reason, so you can gradually gain confidence in social situations.

- Start the socializing process with a few people, in a familiar setting, doing a quiet activity. As you gain energy, you will be less tired and less easily distracted. You can then increase the complexity of social situations. Remember that crowds, noises, and some kinds of light can affect some survivors.

- Learn from past events. If a situation does not go well, ask yourself: What happened? How was it set up? Was there anything you could have changed to make it easier? Be positive. Wisdom comes from experience, and experience comes from making mistakes.

## Establishing New Friendships

Spending time with friends is one of the most rewarding parts of life, but changes caused by a brain injury often result in old friends drifting away. They may not understand your changed behaviour or may not accept the changes.

If your friends are drifting away, it is easy to be angry with them. Often we choose our friends on common interests, so it is not surprising that when the common interests disappear, so do the friends. You should make every effort to find new friends with new common interests. A good way to start is by finding new activities you enjoy doing. Leisure activities and volunteer work provide social settings where common interests may be discovered. Shared interests are the basis of new friendships.

### *Family Matters*

Loss of friends is especially devastating for children and adolescents. Unfortunately, it is a common experience for young people with any type of disability. There are no easy answers, but there are things you can do:

- Concentrate on the abilities your child has and use that to foster new friendships based on common interests.

- Emphasize abilities and do not be discouraged by the initial reaction of others.

- Provide your child with opportunities to interact with their peers just as you would any other child.

- Engage your child in activities they enjoy. If you need an extra pair of hands to enable them to participate, ask local church groups, Guides and Scouts, or mentor programs. For more suggestions, contact Children's Services about the provincial programs for children with disabilities or talk to your child's school.

- Look to your extended family. Your child's deepest friendships may be with cousins, aunts, uncles, or grandparents.

In your efforts to build new friendships for your child, concentrate on developing quality, rather than quantity, in relationships.

## Staying Active

Since many people do not return to work following a brain injury, or work less than full time, it is important to find meaningful activity. Changes in your abilities can make this a challenge. Your family can be a great help by providing coaching, feedback, and instruction. There are also outside resources available, such as your local Alberta Brain Injury Network office (see Resources). Do not hesitate to seek assistance.

## Recreation and Leisure

The brain injury may affect what you do for fun. For example, fatigue may affect your ability to participate in some leisure activities, while a loss of social skills may affect your ability to enjoy these activities with others. To adjust to the changes affecting your leisure activities try:

- being open to participating in new ways. For example, if you enjoyed curling before the injury but are no longer able to curl, consider getting involved as a spectator or volunteer.

- modifying an activity you enjoy to fit your current abilities. For example, if you loved playing cards but now have memory and concentration problems, look for card games where chance is more important than memory.

*Family Matters*

Find a "leisure buddy" to accompany the survivor to various activities. In addition to helping the survivor develop self confidence, a leisure buddy can give you a few hours' rest.

If you need guidance, contact your local Alberta Brain Injury Network office (see Resources) and ask them to direct you to a recreational therapist. If you live in a larger community, call the municipal recreation and/or leisure services department, and ask about services and facilities in your area.

## Volunteering

Once you are physically able to do more, it may be helpful to participate in volunteer activities. Volunteering will give you a chance to do something for others, and it can boost your self-esteem and help you get back into a structured daily routine. Some survivors have said that volunteering is critical for bridging the space between recovery and work. Check out the volunteer opportunities in your community. Just be sure to look for volunteer opportunities that match your activity level and social skills. Your local brain injury association (see Resources) may provide a volunteer program to help you get started.

If you hope to return to work eventually, you will need to work on regaining as many skills as possible. For example, social skills and energy levels are critical to a successful return to work. Begin by developing a daily schedule that includes meaningful activities (such as leisure and volunteering) as well as activities designed to help you practice and improve your skills. This will help your recovery by providing structure to your day. You should probably begin with just one or two hours of structured time in your day and slowly increase this. This will also help you work on your organizational and time management skills, and it will help you discover what your best "daily method of operation" is. For example: Do you work best if you take a five-minute break to stretch once every half hour? Does a computerized daily planner work better for you than a booklet? Do you work better first thing in the morning or late in the evening?

For more information, refer to chapter 10 "Work."

*Family Matters*

## Maintaining Your Family's Social Life

It is important for family members to maintain social contact with others. If you are the caregiving spouse:

- do not quit your job unless absolutely necessary;

- balance your need to talk about the stress of your situation with your need to talk about other things;

- schedule social activities for yourself and follow through;

- arrange for respite care to give yourself a rest (see the "Housing" chapter).

Studies have consistently shown that people with strong social networks manage stress much better. If friendships disappear, establish new ones by participating in one or two social interests or hobbies, or by joining a support group for families of survivors of brain injury. Your local brain injury association (see Resources) should be able to direct you to one of these support groups.

## Survivor Matters

### Driving

Upon discharge from the hospital, many survivors of brain injury should not be driving. Reflexes are slow, decision-making is slow, and judgment is impaired. You may also have light sensitivity and visual problems that you did not have before. These changes, however, may be subtle. It is not uncommon for them to go unnoticed at first, by yourself, your family, and your doctor. In fact, it may take time to realize that you should not be driving or should only drive in light traffic. You should be careful to evaluate your driving skills and decide whether you should wait before beginning to drive again. It is especially important considering that your brain is still in very delicate condition and even a small accident may be dangerous for you. You may want to contact your local Alberta Brain Injury Network office (see Resources) to find out if there is a driver-retraining program available in your area.

Alberta law requires that if you have a condition likely to affect your ability to drive, you must notify your insurer and the Alberta Driver Control Board.

On discharge from the hospital, your doctor will usually advise you and your family on whether it is safe for you to drive. In either case, the Alberta Driver Control Board must be notified.

To notify the Alberta Driver Control Board, you can either contact them directly (310-0000), or contact your nearest license and registry office (check the yellow pages) and explain your situation. They will provide forms for you and your doctor to fill out. They will then review the information from your doctor and determine if you may drive. When leaving the hospital, if the doctor tells you that it is safe to drive, it is legal for you to continue driving until the Alberta Driver Control Board makes a determination.

### *Family Matters*

Because you deal with the survivor every day, you may realize it is unsafe for them to drive even though your family physician believes it is safe. This can be stressful if you are advocating having the survivor's license removed against their wishes and those of other less involved family members. In this case, a driver evaluation may prove useful.

You may call the Alberta Driver Control Board (310-0000) and make an anonymous request to have the survivor evaluated for their ability to drive.

For many survivors, losing their driver's license is a major blow to their independence, especially if they live in a rural area. You and the survivor may need support to work through the process. Get in touch with your local brain injury association (see Resources) or other health professionals in your area, or talk to other families of survivors.

# NOTES

# NOTES

# Paying the Bills

- Paying the Bills
- Help With Paying the Bills
- What if you are not Satisfied
- Helping the Survivor Handle Money

8

# CHAPTER 8

# Paying the bills

**In this chapter, you will:**

- Discover who can help you pay bills and how to appeal for more resources.

- Find out about the different possibilities for managing the survivor's finances.

## Survivor Matters

## Paying the Bills

A brain injury may change your family's income and monthly expenses. Changes will depend on many things. Were you insured? Will you be able to take care of yourself? Do you require special devices to get around, to talk, or to take care of yourself? Are you eligible for a disability pension? Will you need to find a new place to live? Do you need help going back to school or work?

Finding out who pays for what and taking care of your money in the early stages of recovery can be overwhelming. It is good to have an advocate to do these things for you, but it can be an extra burden for family members. Businesses and government agencies try to be friendly and open, but for someone unfamiliar with insurance and health care it can be stressful and confusing. Knowing something about your choices can make paying the bills less stressful.

In this chapter we review possible places where you can find financial assistance. We also talk about things you can do if you think you are unable to handle your own money. Please note that this information is not meant to replace talking with lawyers, financial planners, or other experts in these areas.

# Help With Paying the Bills

## Insurance Coverage

You may be eligible for insurance coverage. The most common policies are:

- The Workers' Compensation Board, which covers persons injured at work.
- Canada Pension Plan Disability Pension, which provides a disability pension for those with a work history.
- Private disability insurance from the survivor's workplace.
- Private disability income plan carried by the survivor.
- Home or other policy where the person was injured. For example, school boards have insurance to cover injuries that occur during school events.

First consult the insurance representative concerned about the benefits of your policy. In order to receive benefits, some sort of application is necessary. Often health professionals must fill out forms on your behalf. Some benefits are very clearly spelled out in a policy. Other benefits are less clear cut. More documentation will be necessary to show the need for unusual or expensive items that could possibly be covered by insurance.

It can be extremely helpful to consult a lawyer experienced in the area of brain injury and insurance regarding the interpretation of insurance policies, especially private policies, in order to ensure that you receive all the benefits you are entitled to.

## Social Assistance

If you or your family no longer has an adequate income, social assistance may be able to help. If your brain injury is considered permanent and severe and leaves you unable to work, you may be eligible for AISH (Assured Income for the Severely Handicapped). To find out if you are eligible for AISH, call 310-0000 and ask to be connected to the nearest AISH office. You will need to bring your complete personal, financial, and medical information when you meet with an AISH intake worker.

If you are not eligible for AISH, but you need an income, or income supplement, you may apply for SFI (Supports For Independence). This helps you pay for basic needs such as food, clothing, and a place to live. Call 310-0000 to find out where the nearest office is, and bring complete personal and financial information.

People who live on a First Nations reserve must apply for social assistance with their band office.

If you do not qualify for social assistance, you may still be able to receive extended health benefits intended to cover certain medical expenses for lower income families. You can phone 310-0000 to find out how to apply for extended health benefits.

Asking someone else to pay for things is not easy. It may be helpful to follow these guidelines:

- Learn what the insurance plan or program covers.

- Be assertive when asking for what you want. Under the stress of having to ask for help, some people will avoid asking for what they need. They risk not getting it. Others grow angry when they are uncomfortable. Growing angry can harm your relationship with your worker or representative, so it is important to stay calm and polite at all times.

- Look to professionals to help you make your requests. Many times a representative cannot agree to pay for something without a letter from a professional.

- When making telephone calls or office visits, use an advocate whenever possible.

## What if You Are Not Satisfied

If you feel you are not getting the benefits that you are entitled to, you may file an appeal. When you appeal, you may not get what you ask for, but you may help those who come after you. You may also risk creating some hard feelings. This is something you should consider before filing an appeal. General points on handling a disagreement are discussed in the School chapter. It may be helpful to think about them here.

Remember, insurance companies only provide the benefits stated in their policy. They do not have to pay for things because they will make your life easier, even if it is a medical necessity, unless those benefits are described in the policy.

The Workers' Compensation Board has a "Workers' Advocate" who helps the survivor and the family appeal decisions. This service is free. The advocate does not have the power to reverse a decision but will be able to help you with the appeal process. You can contact the Workers' Advocate by calling the Workers' Compensation Board. The number can be found in the telephone book, under Workers' Compensation Board, Alberta.

You may feel that you are not satisfied with assistance from a plan or program. In this situation, you may look to someone else to help you present your case. Your local Alberta Brain Injury Network office (see Resources) may be able to help you find an advocate. Call your Regional Health Authority and ask if they have anyone who could provide guidance for you. Rehabilitation Practitioners have lots of knowledge in this area and can be great advocates when available. Tips on finding a lawyer are in the "Finding Help" section of this chapter.

*Family Matters*

### Helping the Survivor Handle Money

Sometimes a survivor is no longer able to make good decisions for themselves. This is called incompetence. If the family believes this is the case it may decide that someone else should make choices for the survivor. There are several ways to do this.

## Power of Attorney

A general Power of Attorney gives a person other than the survivor complete control over the survivor's property and finances. The survivor must have the capacity to grant this power. In legal terms, capacity means that the survivor is aware of what they own, knows who they are responsible for, and can decide who they trust. The survivor appoints an attorney to make the survivor's financial decisions and manage their property. In the event of the survivor's death, Enduring Power of Attorney ends. The attorney must then account to the personal representative of the deceased survivor's estate.

As the law and its interpretation by the Courts frequently change, you will need to contact a lawyer, or the Office of the Public Trustee to ensure that you have the most current information about Enduring Power of Attorney. You may find the publication "Enduring Powers of Attorney Booklet" helpful. You can order it from the Office of the Public Trustee by dialing 310-0000.

Sometimes, after a brain injury, the survivor does not have the capacity to grant Power of Attorney. In that case, trusteeship or guardianship are the only choices.

## Trusteeship

An **Informal Trusteeship** is when the survivor gives permission for a cheque to be sent to a relative, friend, or advocate, who will then use that money to ensure that all of the survivor's bills are paid. In many cases this is a convenient method for a survivor who needs a limited amount of help. However, this puts the survivor at risk of theft or fraud, and puts the Informal Trustee at risk of allegations of theft or fraud.

Therefore, it is advisable to consult a lawyer who is familiar with trusteeship issues when establishing even an informal trusteeship and to draw up a written agreement amongst all the parties involved.

A **Trusteeship Order** is when the court appoints a trustee to manage the survivor's finances and property. The financial guardian's duties include:

- setting up a budget;

- deciding whether the survivor has enough to live on;

- applying for services or investing money to increase income if needed;

- presenting records of money handling to the Courts regularly; and

- presenting records of the survivor's assets and liabilities.

This is a very secure form of trusteeship.

It also requires the trustee to keep very accurate records and appear every six years for a review of the Court Order and to file accounts with the Clerk of the Court every two years. The disadvantage of a Court appointment, however, is that it puts limits on the survivor's rights.

Because of the amount of work involved, sometimes someone outside the family will be asked to be the financial guardian. The Office of the Public Trustee can be the financial guardian if there is no one is available to be the trustee. Call 310-0000 for more information on Public Trusteeship.

There are also some other options. A trust company is usually chosen if the survivor owns a lot of money or property. The company will charge the survivor's estate to pay for their services. All trustees are allowed to charge for their services and it is a polite gesture to offer to pay your trustee a small amount, depending on what you can afford, even though they may decline to accept it.

To apply for trusteeship you will need to consult a lawyer. The lawyer will inform you of your options and tell you the costs involved. Because the law and its interpretation by the Courts frequently change, a lawyer is the best person to consult regarding the most current laws about trusteeship.

## Guardianship

Under the Dependent Adult's Act, one or more family members can become guardians of the survivor. A **Guardianship Order** is when the Court appoints a guardian to make personal decisions for the survivor. A guardian can make all the personal decisions, or just some if the survivor can make some decisions for him/herself. A guardian also often acts as an informal trustee or a formal trustee, although this may not be necessarily the case.

A guardianship order is usually intended to continue for the rest of the dependent adult's life. But since, in the case of brain injury, the survivor may regain many of their skills, the necessity of guardianship may need to be re-evaluated periodically.

A Court decides who will be a guardian and what their duties will be. If you wish to apply to be a guardian you need to follow these general steps:

- Get a copy of the application form for guardianship from a lawyer, the Queen's Printer, or the Office of the Public Guardian and complete it.
- Speak to the doctor caring for the survivor, and request that the doctor write an opinion letter as to the survivor's competence.
- Submit the forms and other documents you have gathered to the Court of Queen's Bench.

Applying for guardianship takes time, and there is a lot of paperwork. It is not a difficult process if there is no disagreement about who should be guardian. The forms have been designed so that anyone can complete them, but many people prefer to work with a lawyer. There are also costs involved in filing for guardianship and for the Court order. If you hire a lawyer, you will have to pay the lawyer's fees as well. You can get these fees back by charging the fees to the survivor's estate.

If you become a guardian, you need to decide what will happen in the event of your death. You can specify a replacement guardian in your will.

If the survivor is a parent with children under 18, provisions may need to be made for the care of those children in the event of the death of the other parent. It is possible for the other parent to specify in a will that a person other than the survivor should serve as guardian for children under 18. Such a provision would be subject to a legal challenge by the survivor.

Finally, because the law and its interpretation by the Courts frequently change, you will need to consult a lawyer, or the Office of the Public Guardian (310-0000) to ensure that your information about Guardianship is accurate and up-to-date.

## Discretionary Trusts

Discretionary trusts may be of interest to families who want to leave money in their will to a survivor who receives social assistance. Generally speaking, any additional income that you provide to the survivor will decrease the amount of social assistance the survivor receives. You may want to provide a better quality of life for the survivor, but find that you are prevented from doing so because of the restriction of social assistance. In this situation, a discretionary trust may be set up in the wills of the people who would like to provide extra funds to the survivor. With a discretionary trust, money is given to a trustee who dispenses the money to provide an improved quality of life for the survivor. You should consult a lawyer to ensure that the discretionary trust in the will is properly drafted.

# Survivor Matters

## Case Managers

A case manager is a professional who helps people find the services they need. A case manager could find you a place to stay. They could help you get financial assistance. They can make sure you get a referral to the right health professional. A case manager can sometimes help with financial or legal matters. Unfortunately, there are not many case managers available for this sort of work. Your local Alberta Brain Injury Network office (see Resources) may be able to help you find a case manager. Sometimes community social workers will act as case managers. However, there are situations where knowledge of the law or of finances is very important. In these cases you should think about hiring a lawyer or a financial planner.

Rehabilitation Practitioners (persons with degrees or diplomas in Rehabilitation Studies) are often good choices for case manager, since they usually know something about the areas in which a person with a brain injury requires assistance.

## Lawyer

Lawyers know about laws, how Courts work, and how to make a legal case. They can be very helpful when you need someone to represent you. Lawyers can be very strong advocates. A lawyer could be of help in the following situations:

- arranging power of attorney;
- seeking guardianship;
- writing a will;
- setting up a trust fund;
- learning about legal rights or insurance inside and outside of the province;

- learning about insurance coverage and obligations; and

- bringing suit against someone. In some cases where the brain injury has occurred through the fault of another person (particularly, where adequate insurance coverage is not available), it may be necessary to consider taking legal action for compensation. A lawyer should be consulted in order to decide if it is worth your while to go to Court.

Choosing a lawyer can be difficult. There are several steps you can take to make sure you get the right one:

- Ask your local brain injury association to recommend a good lawyer who is familiar with brain injury.

- Contact the Law Society of Alberta at 1-800-661-1095. It has lists of lawyers who work in certain areas. Lawyers themselves ask to be placed on certain lists based on their particular area of practice. Names on the list are given out on a rotational basis so that each name is given out an equal number of times. Since most lawyers have one or more areas of specialty, most are on several lists.

- Choose a lawyer and arrange a meeting. Most lawyers will talk with you for half an hour at no charge. They will tell you how they can help. Ask about legal fees in the first phone call or meeting.

- Ask if you can speak to a satisfied client.

Once you have chosen the lawyer you will work with, here are some other things to keep in mind:

- Find out how much experience the lawyer has had working with brain injury. If the lawyer has not had any experience, you may consider choosing another lawyer.

- Make sure you get everything in writing, before you commit to working with a particular lawyer. This should include all fees, all services to be performed, all percentages to be paid to the lawyer, and what happens if you lose your court case.

- Make sure that your lawyer uses an experienced financial forecaster if you are required to determine how much money you will need to live on for the rest of your life.

- Tape-record all of your meetings with your lawyer. You may also consider bringing an advocate with you to the meetings.

- Verify main points at the end of each meeting.

## Financial Planner

A financial planner helps people decide how to manage their money. There is no legal standard as to the qualifications necessary to call yourself a financial planner. Banks, insurance companies, and brokerage firms all hire people with different backgrounds to do this job. Some planners offer advice for a fee and sell products, others only sell products. Some things you can do when choosing a financial planner include:

- Contact the Canadian Association of Financial Planners at 1-800-346-2237. They have a list of qualified financial planners.

- Talk to a chartered accountant. They may be able to help or may be able to suggest someone who can help.

- Ensure that the financial planner that you use is familiar with brain injury and any benefits that apply to your situation.

- Visit some financial planners. Ask what their qualifications are. Ask them about their experience in the area that you need help with. Be clear about the kind of advice you need.

- Ask to speak to a satisfied client.

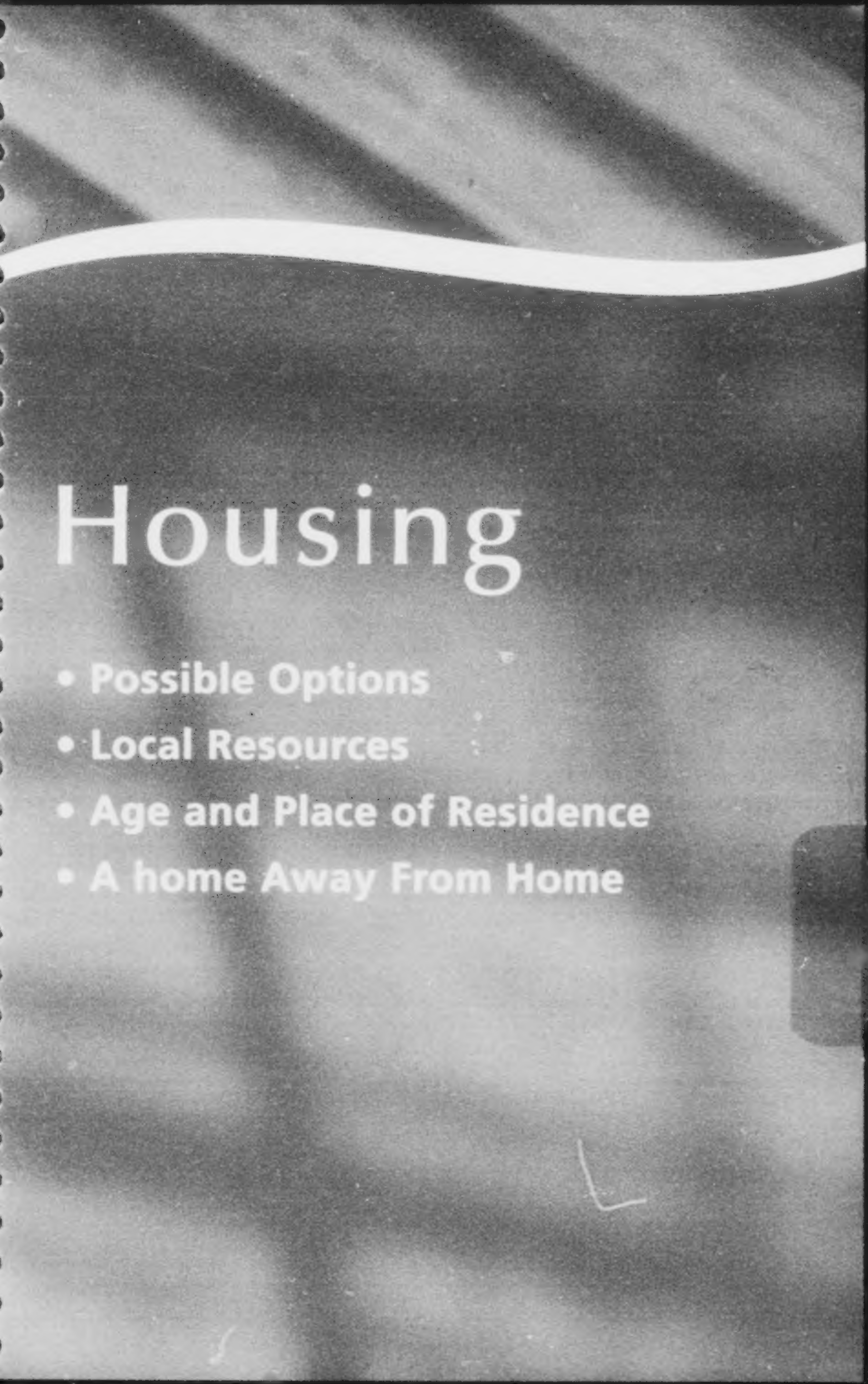
- Get everything in writing before you commit to working with a particular financial planner. This should include all fees and all services to be performed.

## Credit Counseling

You can get free credit counseling through a Government of Alberta sponsored service for those having difficulty paying pills, or managing finances. Call 310-0000 for more information.

# NOTES

# NOTES



# Housing

- Possible Options
- Local Resources
- Age and Place of Residence
- A home Away From Home

9

# CHAPTER 9

# Housing

**In this chapter, you will:**

- Learn about all the options where you could live and get supports.
- Discover how to locate residential supports and resources.

## Survivor Matters

### Possible Options

Deciding where you could live is a major decision, both for you and your family. Your age, severity of the injury, and the availability of resources will influence your decision.

There are a number of options regarding where you choose to live. You may:

- live independently;
- live independently with informal support from the family;
- live independently with formal support from an agency such as Home Care or a private agency;
- live in a transitional setting;
- live in an institutional setting.

*Family Matters*

**The family of the survivor may:**

- provide all care;

- provide care with informal help from the extended family and friends;

- provide care with formal help from Home Care or a private agency; or

- provide care with informal or formal arrangements for respite.

### Respite

Respite gives you a rest from caregiving duties. Informal arrangements may include having another family member (other than the primary family caregiver) provide care or having the survivor go to someone else's home for a period of time. Formal respite may range from having someone from Home Care or a private agency come in a few hours a week to having the survivor spend several weeks at a group home, personal care home, or special care home.

## Survivor Matters

### Local Resources

Your local Alberta Brain Injury Network office (see Resources) can help you identify available residential options and resources in your area. You could also ask the health professionals working with you and your family for a referral to an agency such as Home Care. You can also find Home Care listed in your local telephone book or by calling your Regional Health Authority. Home Care coordinators in your area will know what services are available through your Regional Health Authority and through private agencies.

In addition to lodging, private agencies may offer nursing care, personal care, homemaking help, supervision, or companionship. Check your insurance policies to see if any of these services are covered, especially if these services are not provided by Home Care.

## Age and Place of Residence

Your age is significant in the decision of residential options. Small children almost always go home, even with very severe brain injuries. Because of their small size, the family is usually capable of providing the physical care needed. More importantly, many feel a family setting provides the best environment in which to help the child reach their maximum potential. As the child grows, the family's capabilities grow as well, allowing them to adapt and make plans for the future. Older children and adolescents usually go home, especially if they do not require heavy physical care. Home and school become the rehabilitation environment and allow for as normal a life as possible.

For a young adult who had been living independently, the decision is more complicated. Depending on abilities, it may not be safe for them to continue living independently. If the decision is made to move back to the parental home, adjustments need to be made. Older parents may be unable to provide the supervision needed, or the young adult may resist parental authority and supervision. For an adult with children, the needs and safety of everyone in the family must be considered. For an elderly adult with a spouse, the physical and mental ability of the spouse to provide the required level of care must be considered.

Every family is different. The decision you make must be the one that works best for you.

### Keep Your Options Open

It is not uncommon to try several residential options in the first few years. As you go through the stages of recovery, your family will discover the extent of their care-giving capabilities and limitations. Your first decision may not be the permanent solution. You may want to move towards progressively more independent living arrangements. Or your family may need more and more assistance as they exhaust their own physical and mental resources.

*Family Matters*

### Feeling Overwhelmed

It is normal to feel overwhelmed by the needs of the survivor. However, this does not mean the survivor should not live at home. Discuss your feelings with the health professionals working with you. They are familiar with the emotions you are going through. Talking to them will help you realize that the burden of care is not yours alone. In fact, it may lead you to discover more workable living arrangements.

### A Home Away from Home

There may come a time when a family decides it is best for the survivor to live in a more structured setting. The first step in this process is to contact your local regional health authority. They will put you in touch with the department responsible for arranging such placements (in most cases this is Home Care).

The most common places are group homes, personal care homes, and special care homes. Your Home Care worker or other contact will discuss the options available in your area, as well as any waiting lists. Find out as much as you can about the places you are considering. To do this you can:

- visit the places you think are suitable;
- talk to staff and ask questions;
- talk to some of the people who live there, and ask their opinion;
- visit a variety of homes. It may help you feel more comfortable with the decision;
- discuss together the possible options.

There are currently very few supportive housing options designed for persons with a brain injury. However, it is a recognized area of need, and hopefully more options will become available over time.

## Coping with Guilt

Placing a family member in any residential setting outside the home, especially an institutional setting, can be extremely stressful, and it is not uncommon to experience guilt. Your decision does not mean you are abandoning the survivor. Given the needs of your whole family, it may be the best option. You can remain active in the life of the survivor through regular visits and home passes. You may even find your time together is of higher quality.

Discuss your feelings with the Home Care coordinator or the social worker in the survivor's new home. Talk to friends who have had to make the same decision, or get in touch with a local brain injury association support group (see Resources).

# NOTES

# NOTES

# Work

- Returning to Work
- Signs of Readiness
- Returning to the Old Job
- Looking for a new Job
- Keeping the Job

# CHAPTER 10

# Work

**In this chapter, you will:**

- Read the steps that may gradually enable you to return to work.
- Learn about looking for and keeping a job.

### Survivor Matters

## Returning to Work

Work is important to all of us. It brings in money to pay the bills. It helps give us an identity. It lets us do something meaningful. It is not surprising that many survivors want to return to work as soon as they can.

Returning to work after a brain injury is not easy. Studies show only 1 in 2 survivors who needed help returning to work were still employed at the end of a year. Of those who were employed, only half were in the same job that they started at the beginning of the year. A different study showed that if a survivor did not return to work within six months after the injury, they would likely never return to work. This will depend on the individual, the injury, the job, and many other factors. Giving yourself time and using whatever resources are available will improve your chances of returning to work successfully.

It is also true that your chance of keeping a job is higher if you were highly trained or experienced before the injury or illness. This does not mean that you will return to your old work. Most survivors return to jobs that require much less training or skills. In fact, survivors have been most successful at keeping what are called entry-level jobs.

Many survivors may never return successfully to the work place. Those who do return usually go back to a job with less money and status. Also, if your job provides medical benefits, they will usually not cover a pre-existing condition such as a brain injury. These situations may be very hard for you to adjust to.

It is important to know that there can be other difficulties, even when the return to work is successful. Sometimes the survivor and their family believe that things will get better once the survivor has a job. This is not always the case. It is important to remember that starting a new job is always stressful and more so for someone with a brain injury. You will be more tired. You will be learning a new job or relearning an old one. You will be interacting with more people. You may also be coping with fears of failure. You and your family need to be prepared for the possibility that the job will make things more difficult at home. It is important not to put job success ahead of your family. Survivors often work hard at their jobs at the expense of their family and as a result end up losing their family. Then, without the support network of their family, their career falls apart as well. If your family life is suffering, it is probably a sign that you need a more gradual transition into the work world.

### *Family Matters*

It is important to understand that when relearning a job, some of the survivor's social skills with the family may regress. It is important to be patient at this time. Be sure to communicate to the survivor any changes in the way they are behaving to the family, as they may not be aware of it. If their behaviour has undergone changes, suggest that they slow down their transition back to work.

### Survivor Matters

There are many questions that need to be considered when deciding whether to return to work, such as:

- How do you know when you are ready to go back to work?
- What is the best way to return to work?
- What help will you need when you return to work?
- Who can help you?
- What happens if the return to work is unsuccessful?

## Signs of Readiness

The signs that you are ready to return to work are different from person to person, and they are relative to the job that you will be returning to, as well as to the type of boss and co-workers you have. In general, you are probably not able to return to work until you see some, or all, of the following signs:

- you have enough energy to work at least a half day,

- you can carry a conversation, know how to act towards others, and can pick up important social cues (like when a person is upset);

- you can plan and follow through on simple tasks;

- you use aids, like a daily planner, when necessary;

- you are able to control your temper;

- you are able to recognize your own mistakes;

- you are able to initiate work on your own. (This may be more important in some jobs than in others. Also, you may be able to get support to help you with this).

## Returning to the Old Job

When you try to return to work, your old job may be considered first. This is most likely to happen when:

- you had been in the old job a long time and knew it well;
- your insurance plan states that you must try to return to your old job first;
- your last employer is committed to you;
- you have problems with new learning.

The last point is important because learning new information is difficult for many survivors. Returning to your last job means you do not have as much new information to learn, although you may still have difficulties with relearning information.

Even when returning to an old job there are many things to consider. How many hours a day should you work at the start? Do work hours need to be changed? Should you begin with only some tasks? Which tasks should those be? Do there need to be changes to the workplace or to your work station?

When considering returning to the old job the following is generally recommended:

- Gradually return to work. Begin with a few hours a day or week, and slowly increase the work time over weeks, months or even years. No matter how much you want to go back to your old hours, force yourself to take it slowly. You may not know your limitations yet, and it is better to set yourself up to succeed than to fail.

- Gradually phase in different job tasks. You should start with the simplest and most frequent ones and build to the more complicated and uncommon ones.

- Ask to change job demands to help you cope with your disabilities. Be sure to use empowering language when you do this. You are not asking for special treatment; you are asking for an adjustment that will give you the chance to produce equal work. Some examples of this might be: asking for a work station where noise levels are low, distractions are at a minimum, and lighting is appropriate. You might also ask for an extended timeline for assignments, if you do your best work when only working a few hours a day. Use devices like daily planners, earplugs, canes, or compensatory skills such as: scheduling rest time into your day, or tape recording important meetings so you do not have to rely on your memory.

### *Family Matters*

- You may need to introduce the survivor to compensatory devices and skills. Try to introduce them to as many alternatives as possible (although not all at once) and let the survivor choose the ones that work best for them.

### Survivor Matters

Sometimes the return to the old job does not work out. This is most likely to happen where advanced work skills are needed or where the costs of making mistakes are high. For example, a surgeon is less likely to successfully return to work than a store clerk. Surgeons need to remember lots of facts about people's health. They must also make good decisions when performing surgery. The cost of a mistake in their work could be a person's life. The store clerk needs to know how to work the till. They do not make life and death decisions. If they make a mistake, there is little chance of harm to others.

Your employer may be willing to give you a different job if your old job does not work out. If this happens, it is important to look for a new job that fits your strengths.

Use of an occupational therapist or vocational counselor to help set up the return to work is usually recommended. They can prepare your work place, help you anticipate problems, and help negotiate the return to work. As well, they may be able to arrange a support person or job coach to assist you with your initial return to work. Also, there are often tests and interviews to decide how ready you are to return to work.

## Looking For a New Job

There are many reasons why you might choose to look for a new job. These reasons include:

- possibility of failure at your old job;

- loss of key work skills that do not allow returning to the old job;
- loss of the old job (like when absence from work leads to replacement).

There are professionals who can help you assess what skills you will need to be successful at various jobs. Most employers will not provide you with an occupational therapist or vocational counselor but there are some organizations that provide these services to survivors for free (see Resources for the contact number of your local Alberta Brain Injury Network office). You might also get help with this from your rehabilitation centre or hospital. If you have the financial resources, you could hire a professional vocational counselor or occupational therapist to help you with your return to work.

An occupational therapist or vocational counselor will often take the following steps:

- **A vocational assessment:** This usually involves testing to discover what job skills and interests you have. It may also include short job placements.

- **A neuropsychological assessment:** The tests used in this assessment measure your thinking ability. This includes abilities like memory and attention. There is a possibility that this test will group you in the normal range. But, ultimately, your day to day functioning after the injury is a better measure of how you have been affected.

- **Job skills training:** Some places offer training in job skills needed for any workplace. This includes skills like being on time, being respectful, dressing correctly, and learning your job.

- **School or retraining:** Before starting a new job it is sometimes necessary to get more education. This education usually teaches you how to do a job that you have never done before.

- **A job try-out:** Many survivors have trouble taking what they have learned in one place and using it in another. For these survivors, it does not make sense to learn about a job in the classroom. They need to learn on the job. A job try-out also shows whether you work fast enough and well enough to get a paid job, as well as whether you would enjoy the work. Finally, the try-out can reveal how much support you may need to get or keep a job.

- **A job search:** A job search involves writing a resume, looking for jobs, speaking with employers, applying for jobs, and going to interviews. There are programs that help with this. Check with your local Alberta Brain Injury Network office (see Resources) to find a program near you.

Some people will need help only with the job search. Others will need help with all of the steps. You may need something in between. The amount and type of help needed is usually decided based on testing, your wishes, and the results of job try-outs or education.

## Coach

Most survivors need some help in returning to work. A vocational rehabilitation counselor or an occupational therapist is usually the best support. These professionals can be of most help if they know both about brain injuries and the job market.

Many people will also need a **job coach**. A job coach spends time helping you learn the job. They also help you to see how well you are doing on the job and how well you are getting along with others. Social skills are the biggest reason for success or failure in jobs. You may avoid the lunch room because it is so noisy and crowded that it exhausts you, making it difficult for you to concentrate in the afternoons. Other people may think that you always eat lunch in your office because you do not like them. A job coach can help you see these problems and may be able to suggest alternative solutions, like inviting a few of your co-workers to eat in your office with you, and explaining to the rest of your co-workers your problem with crowds.

The job coach may work alongside you for some time. This will only happen if your employer is willing. This may be needed where there are deadlines or work quotas. This support may continue until you can work efficiently enough on your own.

If the job try-out works, you might have a job. Sometimes it is necessary to try working in several places. By trying out several jobs as part of the assessment, you will be better able to see what sort of work best suits you. Job try-outs can also help you practice important work skills, like getting to work on time and listening to the boss.

## Keeping the Job

Finding a job may be easier for survivors than keeping a job. The most common reasons for losing a job are:

- poor conduct (temper problems, social problems);
- poor attendance (coming late too often or missing work);
- high levels of distress experienced by the survivor.

Having someone like a job coach can sometimes keep these problems from resulting in losing your job. The job coach can increase your awareness of potential problems and help bring about change. They can also educate your co-workers and employer about brain injury. Long-term follow-up is also important. Often when the survivor starts work, co-workers and employers put up with poor conduct, rather than talk about the problem. Then one day they get fed up and fire the person. Follow-up has to be long enough to cover this possibility. Even if you do not have a job coach, try to keep the communication open. Ask your boss and co-workers questions like, "How have I been doing this week? Is there anything I could improve on?"

There are no guarantees of staying in a job, but specialists tell us that there are some things that are more likely to lead to success. The most important is social skills. Social skills include talking with others, knowing how they are feeling, and treating them with respect.

Other qualities that will help you to get and keep a job include:

- having well defined job interests and abilities, and considering them when choosing a job;

- being assertive rather than aggressive;
- being able to move about well and having good vision;
- being able to work on your own for a long time;
- using strategies to help with problems like memory;
- enjoying your job;
- having a good support network;
- having good communication and social skills.

# NOTES

# School

- Returning to School
- What to Expect for Your Child
- Your Role as Parents
- Working With the School
- Handling Disagreements With the School
- The Importance of Early Intervention for Young Children
- Grief, Guilt and Depression

# CHAPTER 11

# School

**In this chapter, you will:**

- Learn how to deal with the difficulties ofreintroducing your brain injured child to the school system.
- Read how to minimize misunderstandings or disagreements with teachers, principals, and aids by discussing plans and options in advance.

*Family Matters*

## Returning to School

In the case of a child with a brain injury, both the family and the child may be eager for the survivor to return to school. There are resources available to assist in this transition:

- In the education system, most school boards provide special needs services, so your child does not necessarily have to attend a specific school. The manner in which schools provide services, however, may vary.
- Your local brain injury association (see Resources) can be of assistance when your child returns to school. These professionals can provide education on brain injury to your school, consult with teachers, and provide a link to the hospital and other medical services.
- Health Professionals. The health professionals most likely to be involved with your child's return to school are psychologists, speech language pathologists, and

occupational therapists.

Brain injury associations, health professionals, and the education system should work as a team with the family and child.

## What to Expect from Your Child

The following changes may affect your child's return to school. This is not an exhaustive list. Your child may experience many of these changes or none at all:

- fatigue;
- irritability, angry outbursts, and impulsiveness;
- passive behaviour;
- depression;
- forgetfulness;
- poor organizational skills;
- difficulty following directions;
- immature behaviour;
- inappropriate sexual behaviour.

## Fatigue

Fatigue is the most common problem in returning to school. Your child may also suffer from vision problems, light sensitivity, or headaches that they did not have before the injury. Because school is a highly stimulating environment, it will be difficult at first for your child to deal with all the noise and activity. This is why many children return to school gradually.

Your child may start by attending a few hours, two or three days a week, without educational demands. As they gain energy, attendance is gradually increased and a curriculum started. Eventually, your child may be able to attend full days, five days a week.

In rural areas, transportation limitations may mean your child is at school for longer periods than appropriate. To prevent fatigue, you may need to arrange for the school to give your child rest periods in a quiet place. Remember, it is important that your child participate in school activities only when they have the mental and physical energy to do so.

## Irritability and Angry Outbursts

Irritability and angry outbursts are also common among children learning how to deal with the stimulation of school. Look at what precedes the behaviour. Do you notice a pattern? Is there something you can change, such as introducing a rest period, that will help prevent or reduce the frequency of the behaviour?

## Immature or Inappropriate Behaviour

Immature behaviours include interrupting frequently, making tactless remarks, displaying messy eating habits, or repeating words over and over. Inappropriate behaviours may include sexual comments or gestures or actions that are out of context. Your local brain injury association (see Resources) may have books in their library that will provide helpful information on coping with these and other behavioural problems.

## Your Role as Parents

Consistency between home and school gives your child the best chance for recovery. As parents, you are the constant in your child's life, the mainstay in changing school and health care environments. Your perspective and input are therefore vital. Talk to your child's teachers about what your child was like prior to the injury and what they are like now. Share what you have learned in promoting acceptable behaviour and helping your child achieve their highest potential.

## Working with the School

Almost all children with brain injuries will return to school. Your school, however, may have had few, if any, children with brain injuries in the past. The more you can assist the school, the better it will be for your child.

Each school board has someone responsible for services to students with special needs. This person will have access to information and a variety of resources to help your child return to school with as much support as possible.

## About Teachers

The classroom teacher and resource room teacher will be the most involved with your child. Although many teachers do not have training specifically for working with students with brain injury, many of the adaptive strategies and teaching techniques used for brain injury survivors are familiar to teachers. Interest, flexibility, and commitment to learning about brain injury are often hallmarks of an effective teacher. The classroom teacher is not an expert in special needs situations; the resource room teacher has more knowledge in this area. The classroom and resource room teachers should work together to create a suitable program for your child.

## Getting Started

When helping your child return to school some tips on getting started may be helpful:

- Contact the principal of your local school as soon as possible after the injury. This will give the school time to prepare.

- Arrange a meeting with the principal. It is the principal that will arrange any assessments that your child will need. They will tell you the process of your school board for reintroducing your child to school.

- Bring background information to the meeting. For example, if you have reports that identify your child's areas of ability and difficulty, bring copies to the meeting. More importantly, bring names and contact numbers of health professionals who can help the school develop an appropriate program. The more information you can give the school, the better program they can design.

- You may also bring a "support" person: a friend, family member, or health professional. The purpose of the meeting is to give the school enough information for it to develop a teaching plan for your child.

- Prepare for the meeting by writing down your short and long term goals. What do you want for your child? What are your child's strengths, etc.? Remember to write down and ask any questions you have.

- You may want to meet with the classroom teacher and resource room teacher.

After the first formal meeting, the school (with your permission) will collect information about your child. This information will allow the school to provide additional services such as: a teacher associate, tutoring, special equipment, and summer programming.

Remember, while it is important for your child to have all the services they need, it is equally important not to think of more services as better service. Think about what your child needs and look for services that best meet those needs.

## The Teaching Plan

A second meeting is needed to discuss the plan for teaching your child. If you do not hear from the school, call and initiate the meeting yourself. It is important that you have an opportunity to discuss the teaching plan with everyone working with your child. Ask for a copy of the plan prior to the meeting. Read it ahead of time. Write down your questions and concerns.

The teaching plan is not meant to be set in stone. Instead, it should have regular review times built into it. It may be helpful to set actual meeting dates for these reviews, but do not hesitate to call your child's teacher at any time.

Reviews will evaluate how well the plan is working in relation to your child's emotional adjustment, functional skills and available peer support. Over time, long range goals may change as your child's abilities become clearer. Formal plans can be made to help prepare your child for expected developments such as a change in teachers, grades, or even schools. Ongoing discussions between you, the school, and possibly health professionals will ensure appropriate changes are made.

## Consulting a Specialist

It may be helpful for you and your child to have a consultation with a neuropsychologist. Neuropsychologists have advanced training in the relationship between brain function and behaviour. Standard psychological tests tend to provide information on past learning, whereas children with brain injuries have problems learning now. The tests used by neuropsychologists provide information on your child's ability to learn, communicate, plan, organize, and relate to others. Such an assessment can provide critical information for building effective and efficient educational plans.

Talk to a health professional, or your local Alberta Brain Injury Network office (see Resources) about whether your child could benefit from a consultation with a neuropyschologist.

## Handling Disagreements with the School

Children benefit most when the parents and the school operate as partners. Because it is in people's nature to see things from different points of view, there may be disagreements.

## What to Do When You Disagree

First and most importantly, in the event of a disagreement between parents and the school it is necessary to remain constructive. Your goal is not to win the argument, but to ensure your child has the best education possible. Here are some general guidelines for handling a disagreement:

- Convey your disagreement to the school calmly. Many disagreements are easily and quickly resolved. For example, you may have information the school does not. Simply giving them that information may resolve the issue. There may have been a misunderstanding, and discussing it with the appropriate person may resolve the issue.

- In most cases, solving problems informally works better than formal appeals. Start by talking to the person closest to the situation, usually the classroom teacher. Outline what you are unhappy about and why. Explain how you would like the situation changed.

- If you are unable to resolve the problem, talk to the principal. If you are still unable to resolve the issue, contact the local school board and talk to the person responsible for student services or the Director of Education for the Board.

- The next step is to take your concerns to the Department of Education, which has regional superintendents for special education. It is unlikely you will need to go this far as most disagreements are resolved with the classroom teacher.

- Finally, if your problems are still not being addressed to your satisfaction, you may want to talk to the Minister of Learning, or Alberta Human Rights. Call 310-0000.

- Remember, disagreements can be an opportunity for more in-depth problem solving and that can lead to improvements for your child.

## What to Do When You Are Emotional

When people relate to each other angrily, the result is often counterproductive. Although it may seem obvious that anger can be unhelpful in dealing with people, where your child is concerned it is not always easy to remain calm. Some guidelines for dealing with situations that make you emotional are:

- Prepare ahead of time by writing down points that you would like to discuss in the meeting. This will prevent you from forgetting any important points, as well as help you to present your concerns in an effective manner.

- Always respond with well thought out arguments. Not only will these help you communicate your point more effectively, but they will take time to develop, and that time can help temper your anger. Remember that the staff at the school are ordinary people trying to allocate limited resources to meet the needs of hundreds of children. Your job is to ensure the best education for your child. Their job is much broader and involves many more people so you will need to be patient.

- Attend the meeting with an advocate who can voice your concerns should you become too emotional.

- If you find yourself getting angry in a meeting, ask for a recess. If necessary, ask to resume the meeting another day.

- A disagreement does not mean you have to be angry. Simply state the point you disagree with and why. You will be a stronger advocate for your child if you present yourself in a credible, professional manner.

- Ask for an agreed upon action plan and don't leave without it. Record the plan in writing, review it with the educator, and leave a copy with them.

## The Importance of Early Intervention for Young Children

Many people assume that an injury in a very young child is less serious than in an older child or adult because of the remarkable recuperative abilities of young children. This may apply to physical problems, but unfortunately, for intellectual tasks such as thinking, problem solving, and planning, an early injury may be more serious. This means that early intervention by professionals is very important.

Children lack the years of learning and experience acquired by older people. An older child or adult can often compensate for learning difficulties by building on past knowledge, whereas a young child has not had the opportunity to lay that foundation.

The nature of a brain injury can also make learning more difficult as time goes by. For example, young children do not have the same capacity to think abstractly as adults may have, so any deficiency in this area may go unnoticed until the age when abstract thinking becomes expected. Due to the brain injury, the child suddenly lags behind his peers. To help prevent this type of situation it is important to have early intervention for young survivors.

## Grief, Guilt, & Depression

Many parents of young brain injury survivors experience grief, guilt, and/or depression over what has been lost. These are normal emotional responses. You need to grieve your losses and so may your child. You may feel guilt over the circumstance of the injury even if it could not reasonably have been prevented. Guilt is often expressed as anger and blame directed at others. Depression is another common response. If you or your child are finding it difficult to move through these emotions, contact your local school board or local Alberta Brain Injury Network office (see Resources) and ask about counseling.

# NOTES

# Sexuality

- Sexuality
- Common Changes
- Coping With Changes

# CHAPTER 12

# Sexuality

**In this chapter, you will:**

- Discover how brain injury can alter expression of sexuality.
- Learn how to cope with altered expressions of sexuality.

## Survivor Matters

## Sexuality

Our sexuality is expressed by our social interactions and the roles we fulfill. When addressing issues relating to adult sexuality, the normal maturational cycles should be considered when reporting unusual patterns or behaviours. Brain injury may alter your expression of sexuality. Mother, father, child, lover, friend, employee, and caregiver are all roles that may be affected by an altered expression of sexuality resulting from a brain injury.

Since many people regard sexuality as a private matter, they are hesitant to bring up the topic. The purpose of this chapter is to let you know that sexuality is an important issue and that it is okay to ask questions.

Concern about your expression of sexuality may vary depending on your age and role at the time of the brain injury. This may be of interest to you if you are married or hoping for a romantic relationship.

Many possible changes or concerns about sexuality can occur as a result of a brain injury. If you have questions about topics not covered, do not hesitate to ask the health professionals working with you and your family or your local brain injury association (see Resources).

## Common Changes

The most common changes after a brain injury include a decreased interest in sexual relationships, impotence, or uninhibited behaviour in inappropriate situations. In all cases, it is important to remember that this behaviour is the result of the brain injury.

Cognitive difficulties are often the source of inappropriate behaviour; such as uninhibited speech or behaviour, poor social judgment, and misunderstanding social cues. You may say things out loud that others think but do not say. For example, where other people may only think in their head that a stranger is good-looking you may bluntly tell this stranger that you find them attractive. You may interpret friendliness as a sexual approach, and then be surprised by the rejection you experience when it is made clear that it was not a sexual approach.

Some changes may leave you vulnerable to exploitation. For example, impaired judgment may prevent you from recognizing a potentially dangerous situation, or you may lack the intuition that tells you when someone who seems friendly is really seeking to take advantage of you.

Social skills are an important part of sexuality, and difficulty with them will affect your relationship with others. If you have memory impairment, show little change in facial expression, or take longer to put thoughts into words, you may find it difficult to form friendships. Limited social relationships will reduce the possibility for a romantic relationship. This can obviously be the cause of much anxiety.

Depression is a common occurrence for both survivors and their families. Being depressed or "feeling down" can influence a person's sexual desire. In this case, you may want to seek help from a professional counselor. Your local Alberta Brain Injury Network office (see Resources) may be able to help you find a counselor.

### *Family Matters*

Parents of a child with a brain injury may find that their sexual relationship with their spouse changes. Stress, fatigue, and intense emotions such as anger, guilt, and depression can affect sexual interest. This can lead to tension in the marriage.

A spouse who becomes a caregiver may find it difficult to maintain a sexual relationship, because the roles of caregiver and lover do not mix easily. Many caregiving spouses report a variety of reasons for their declining interest in sex. They may not have a lot of energy. The survivor's appearance, behaviour, intellectual abilities, and personality may change, and they may no longer be the kind of person the spouse would have chosen as a sexual partner.

Some survivors have a dramatic increase or decrease in their interest in sex. If they have memory troubles and cannot remember when they last had intercourse with their partner, keeping a diary or written log may help regulate a give and take sexual relationship with their partner. If this continues to be a problem, and is creating tension in the relationship you may want to seek professional help.

### Survivor Matters

## Coping with Changes

To prevent inappropriate behaviour and encourage appropriate behaviour, discuss and practice appropriate behaviour for specific situations. Memory difficulties may make it necessary for you to review and practice these lessons frequently. Since you may have trouble recognizing when you are behaving in an inappropriate manner, you may want to establish with your family and friends a discreet signal or phrase that they can use to tell you if you are acting inappropriately.

### *Family Matters*

When the survivor behaves in a sexually inappropriate manner, deal with the situation in the same manner as any other inappropriate behaviour. Describe the behaviour to them, explain why it is inappropriate, and provide an appropriate alternative action. Additionally, you and the survivor could agree on a prearranged signal/cue to alert the survivor when they may be exhibiting inappropriate behaviour. If inappropriate behaviour persists, tell the survivor the behaviour is inappropriate and that you are going somewhere else and will not interact with them until the behaviour stops. The goal is that eventually the survivor will learn how to manage their own behaviour to a greater level.

## Survivor Matters

### Talking About Sexuality

Even though you may not feel comfortable discussing issues of sexuality with others, it is important for you to talk about what is happening and how you are feeling. Speak to a health professional who is familiar with brain injury and its effects, or talk to other survivors and their families. As a spouse, you may have feelings of guilt or anger about the changes in your relationship. These feelings are normal. Talking about them together with a knowledgeable person can help prevent further stress and depression.

# NOTES

# Resources

- Resources
- Regional Network Offices
- Brain Injury Associations
- Internet Resources
- Written Resources

# CHAPTER 13

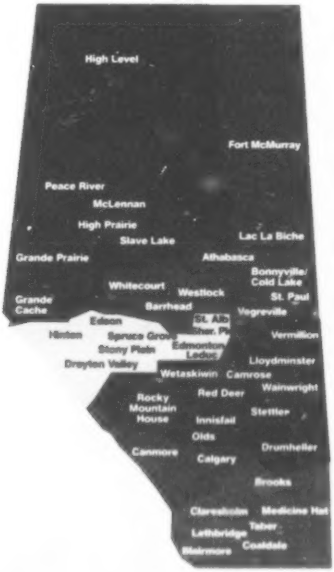
# Resources

**In this chapter, you will:**

- Find out how to contact the brain injury organizations in Alberta.
- Discover helpful books and Internet resources.

## Alberta Brain Injury Network Offices

Following a Request for Proposal process in the Fall 2001, Alberta Community Development has contracted with agencies in six regions of the province to provide support, coordination and outreach services. The Alberta Brain Injury Network was officially launched on May 31, 2002.


High Level
Fort McMurray
Peace River
McLennan
High Prairie
Slave Lake
Lac La Biche
Grande Prairie
Athabasca
Bonnyville/
Cold Lake
Whitecourt
Westlock
St. Paul
Grande
Cache
Barrhead
Vegreville
Edson
St. Alb
Sher. Pk
Hinton
Spruce Grove
Vermillion
Stony Plain
Edmonton
Leduc
Lloydminster
Drayton Valley
Wetaskiwin
Camrose
Wainwright
Rocky
Mountain
House
Red Deer
Stettler
Innisfail
Olds
Drumheller
Canmore
Calgary
Brooks
Claresholm
Medicine Hat
Taber
Lethbridge
Coaldale
Blairmore

The following is a listing by region of the Alberta Brain Injury Network Offices involved in this new service coordination network with the contact information for each.

## Provincial Office

P.O. Box 476
Edmonton AB T5J 2K1
Or:
Message Line: (780) 415-2747
Fax: (780) 422-7533
Website: www.cd.gov.ab.ca
Email: braininjury@gov.ab.ca

## South Region

(REDI) Enterprises/HIP - Brain Injury Relearning Services
828 - 11 Street SE
Medicine Hat, Alberta T1A 1T7
Telephone: (403) 528-2661

Or

Lethbridge Family Services Association
1107-2nd Avenue "A" North
Lethbridge, Alberta T1H 0E9
Telephone: (403) 320-9119

## Calgary Region

Southern Alberta Brain Injury Society (SABIS)
137, 2723-37 Avenue NE
Calgary, Alberta T1Y 5R8
Telephone: (403) 521-5212

## Central Region

A Partnership of Canadian Mental Health Association, Alberta Central Region (CMHA), and Catholic Social Services (CSS), in consultation with Central Alberta Brain Injury Society (CABIS)

CMHA
4, 5015-48 Street
Red Deer, Alberta T4N 1S9
Telephone: (403) 342-2266

CSS
5104-48 Avenue
Red Deer, Alberta T4N 3T8
Telephone: (403) 347-8844

## Edmonton Region

Northern Alberta Brain Injury Society (NABIS)
#301, Royal Alexandra Place
10106-111 Avenue
Edmonton, Alberta T5G 0B4
Telephone: (780) 479-1757

Or

NABIS, Edson Office
Box 20027
Edson, Alberta T7E 1W4
Telephone: (780) 712-2435

## Northwest Region

Northern Alberta Brain Injury Society (NABIS)
#406 - 9728 Montrose Avenue
Grande Prairie, Alberta T8V 5B0
Telephone: (780) 532-0477

## Northeast Region

St. Paul Abilities Network
4915 - 51 Avenue (P.O. Box 457)
St. Paul, Alberta T0A 3A0
Telephone: (780) 645 - 3441

Or

Blue Heron Support Services Association
4925 - 51 Avenue (P.O. Box 4238)
Barrhead, Alberta T7N 1A2
Telephone: (780) 674-4944

The Alberta Brain Injury Help Line has the most complete and updated list of brain injury resources in Alberta. If you are looking for something specific that you cannot find in the following pages, please contact the Alberta Brain Injury Help Line. Someone there will be able to help you with your search.

Alberta Brain Injury Help Line
Telephone: (780) 474-5678
Toll Free: 1-877-474-5678
Fax: (780) 474-4415
Web: www.abihelp.org
Email: helpline@abihelp.org

## Brain Injury Associations

This list only includes the two major brain injury associations in Alberta. The Alberta Brain Injury Help Line (Telephone: (780) 474-5678 or Toll Free: 1-877-474-5678) may be able to assist you in contacting a local association.

Southern Alberta Brain Injury Society (SABIS)
137, 2723-37 Avenue NE
Calgary, Alberta T1Y 5R8
Telephone: (403) 521-5212
Email: sabis@sabis.ab.ca

Northern Alberta Brain Injury Society (NABIS)
# 301, 10106 - 111 Avenue
Edmonton, AB T5G 0B4
Telephone: (780) 479-1757
Toll Free: 1-800-425-5552
Fax: (780) 474-4415
Email: nabis@abihelp.org

## Internet Resources

There are many websites related to brain injury that may be of interest to you and your family. Some sites provide information regarding research, treatment and rehabilitation, while others highlight resources and supports that are available to brain injury survivors and their families.

Whatever you're looking for, it is important to remember that although the Internet can be a great source of information, not all websites are equally reliable. When looking for information on the Internet, keep in mind the following:

* Websites of provincial and federal governments, as well as medical and health professional organizations, are usually reliable sources of information.

* When accessing out-of-province and out-of-country resources, it is important to remember that information regarding laws, benefits and health care

systems may be quite different from those in Alberta.

* In Canada, "brain injury" and "acquired brain injury" are the most common search keywords. If you want to access websites from the United States, try using the term "traumatic brain injury."

* Some websites offer products, services and resources for sale. Before buying anything from a website, show the site to family members or your advocate, or ask someone from your local brain injury association if they are familiar with the site.

* Any information you find on the Internet should not be used as a substitute for advice from a professional. Discuss website information with your doctor, rehabilitation specialist, lawyer, or financial advisor.

## Written Resources

There are huge numbers of books, pamphlets, one-page handouts and magazine articles on brain injury. Contact the Alberta Brain Injury Help Line or your local brain injury association and tell them what kind of information you are looking for. They all have libraries of written information specifically on brain injury, and many of these resources are written for persons with brain injury and their families, rather than medical people. These agencies also have audio-visual material such as videos, and have resources that deal with specific changes, such as memory, planning, and inappropriate behaviour, as well as personal stories from people who have survived brain injury. Personal stories are not only inspiring, they can be reassuring, and can help you see you are not alone. There are many excellent books available; the following resources are a great place to get started. Canadian titles are marked with 🇨🇦

Accessing Community Resources : Discharge Planning
Guth, Mark
Houston, TX : HDI Publishers - 67p. ; 23 cm. (HDI Professional Series on Traumatic Brain Injury , no. 13) 1988

Alex's Journey : The Story of a Child with a Brain Tumor
American Brain Tumor Association
Des Plaines, IL : ABTA - 56p. - ill. 1994

Beyond Difference
Condeluci, Al
Delray Beach, FL : St. Lucie Press - lv, 246p. 1996

Brain Injury Rehabilitation with Children and Adolescents
Ylvisaker, Mark
Houston, TX : HDI Publishers - 65p. - (HDI Professional Series on Traumatic Brain Injury; no. 12) 1988

Brain Injury Survivor and Caregiver Educational Manual
Aspen Reference Group, Sara Nell Di Lima, Dwayne E. Eutsey, Jennifer Carson Vyskoul, editors - 1 v. (looseleaf)
Gaithersburg, MD : Aspen Publishers 1998

Building Communities from the Inside Out : A Path Toward Finding and Mobilizing a Community's Assets
Kretzmann, John P. ; McNight, John L.

Evanston, IL : Centre for Urban Affairs and Policy 1993

Children with Acquired Brain Injury : Educating and Supporting Families
Singer, George H.S.; Glang, Ann; Williams, Janet M., editors
Baltimore, MD : Paul H. Brookes Publishing : xx, 262p. 1996

Cognitive Rehabilitation for Persons with Traumatic Brain Injury : A Functional Approach
Kreutzer, Jeffrey S. and Paul H. Wehman, eds.
Baltimore, MD : Paul Brooks Publishing - 299p. 1991

Collaborative Brain Injury Intervention : Positive Everyday Routines
Ylvisaker, Mark, and Timothy J. Feeney
San Diego, CA: Singular Publishing Group : 330Pp. 1998

Coma, a Healing Journey : A Guide for Family, Friends and Helpers
Mindell, Amy
Portland, OR : Lao Tse Press 1999

Coma : Key To Awakening
Mindell, Arnold
Boston, MA : Shambhala Publications 1989

Coming Home : A Discharge Manual for Families of Persons with a Brain Injury
DeBoskey, Dana S., editor
Houston, TX : HDI Publishers - 63p. 1996

Community Integration Following Traumatic Brain Injury
Kreutzer, Jeffrey S.; Wehman, Paul
Baltimore : Paul H. Brookes Publishing Co. - xiii, 338 p. : ill. ; 26 cm 1990

🇨🇦 Courage after Coma : A Family's Journey
Mathewson, Mufty ; foreword by Barry Miller
Edmonton : Uneek Experience Ltd. 1997

Crushed, but Not Destroyed
Longenecker, Sharon
Boring, OR : Sun Ray Publishing Co., 232p 1984

Developing Self Control
Wesolowski, Michael
Houston, TX : HDI Publishers - 60 p. - (HDI Professional Series on Traumatic Brain Injury; no. 14) 1988

Developing the TBI Rehab Plan
Guare, Richard
Houston, TX : HDI Publishers - 43 p. - (HDI Professional Series on Traumatic Brain Injury; no. 4) 1988

The Diving-Bell & the Butterfly
Bauby, Jean-Dominique, translated by Jeremy Leggatt
London : Fourth Estate 1997

Dr. Weisinger's Anger Work-Out Book
Weisinger, Hendrie
New York : Quill - 222p. 1985

Educational Dimensions of Acquired Brain Injury

Savage, Ronald C., Walcotte, Gary F., editors
Austin, TX : PRO-ED - xxiii, 571p. 1994

Family Guide to Stroke Treatment, Recovery and Prevention
Caplan, Louis R.; Mark L. Dyken and J. Donald Easton
New York : Random House - xiv, 320p.1994

Head Injuries
Aaseng, Nathan; Aaseng, Jay
New York : Franklin Watts 1996

Head Injury : a Family Matter
Williams, Janet K.; Kay, Thomas
Baltimore, MD : Paul A. Brooks Publishing Co. - 320p. 1991

Head Injury : A Home Based Cognitive Rehabilitation Program
Tampa General Rehabilitation Center, Tampa, FL; DeBloskey, Dana S. [et al]
Houston, TX : HDI Publishers - 76 p. (HDI Coping Series on Traumatic Brain Injury; no. 2) 1989

Head Injury and the Family : A Life and Living Perspective
Orto, Arthur E. Dell; Power, Paul W.
Winter Park, FL : PMD Publishers Group - x, 246p. 1994

Hiring the Head Injured : What to Expect
DeBoskey, Dana S., [et al]
Houston, TX : HDI Publishers, 1989 - 55 p. - (HDI Coping Series on Head Injury; no.3). 1989

Interdependence: The Road to Community, Second

Edition
Condeluci, Al
Boca Raton, FL : CRC Press 1998

🇨🇦 The Joy of Not Working : How to Enjoy Your Leisure Time Like Never Before
Zelinski, Ernie J.
Edmonton : VIP Books - 186p. : ill. 1993

Kidnapping Kevin Kowalski
Auch, Mary Jane
New York: Scholastic, Inc. - 124p. 1990

Living with Chronic Pain : A How To Manage Manual for Families of Chronic Pain Patients
DeBoskey, Dana S.; Alberts Jr., Fred L.; Greif, Stuart J.; Morin, Karen; Todd, Dennis
Tampa, FL : Tampa General Rehabilitation Center, Tampa General Hospital - 65 p. 1989

🇨🇦 Living with Stroke : Putting The Pieces Back Together: Participants Manual
Heart and Stroke Foundation 1999

🇨🇦 The Man who Lost Himself
Callwood, June
Toronto : McClelland & Stewart ; 293 p. 2000

🇨🇦 Memory Management Handbook : Useful Strategies for Survivors of Brain Injury
REBUILDING, Edmonton Brain Injury Relearning Society (EBIRS)
Edmonton : REBUILDING - 21p. 1995

🇨🇦 My Year Off
McCrum, Robert
Toronto : Knopf Canada 1998

🇨🇦 The Never Ending Journey Begins : A Guide Through The Intensive Care Unit for Those With Traumatic Brain Injury, Their Families and Their Friends
Maisey, Dayla
Okotoks, AB : D. Maisey 1998

Over My Head : A Doctor's Own Story of Head Injury from the Inside Looking Out
Osborn, Claudia L.
Kansas City, MO : Andrews McMeel Publishing - 239p. 1998

A Programme of Intervention For Substance Abuse Following Traumatic Brain Injury
Corrigan, J.D.; Lamb-Hart, G.L.; Rust, E.
Brain Injury, [1995], vol. 9, no. 3, pp. 221-236. 1995

Rehabilitation of the Adult and Child with Traumatic Brain Injury, Second Edition
Rosenthal, Mitchell; Griffith, Ernest R.; Bond, Michael R.; Miller, J. Douglas, editors. - Forward by Bryan Jennett
Philadelphia : F. A. Davis Company. - xxxviii, 652 p. : ill. 1990

Sexuality and the Person with Traumatic Brain Injury : A Guide For Families
Griffith, Ernest [and] Lemberg, Sally
Philadelphia, PA : F. A. Davis - xii, 170p.1992

Signs and Strategies for Educating Students with Brain Injuries : A Practical Guide for Teachers and Students
Wolcott, Gary; Lash, Marilyn; Pearson, Sue
Houston, TX : HDI Publishers - 101p. 1995

🇨🇦 Slow Dance : A Story of Stroke, Love and Disability
Klein, Bonnie Sherr, in collaboration with Persimmon Blackbridge
Toronto : Vintage Canada 1997

Susan's Dad : A Child's Story of Head Injury
Leaf, Leif E., illustrated by Lisa Widocki
Emeryville, CA : Meadowbrook Rehabilitation Group 1994

Teaching Job Seeking Skills
Wesolowski, Michael
Houston, TX : HDI Publishers - 93 p. - (HDI Professional Series on Traumatic Brain Injury; no. 16) 1988

Teaching Persons with a Brain Injury : What to Expect - Second Edition
Tampa General Rehabilitation Center Houston TX : HDI Publishers (The HDI Coping Series, No. 5) 1996

Ten Days to Self-Esteem
Burns, David S.
New York : HarperCollins 1993

Traumatic Brain Injury Rehabilitation : Children and Adolescents - Second Edition
Ylvisaker, Mark
Boston, MA; Butterworth-Heinemann - 479p. 1998

🇨🇦 Whatever It Takes : A Model for Community-Based Services
Willer, Barry ; Corrigan, John D.
Brain Injury, [1994], vol 8, pp. 647-659 1994

Why Did It Happen on a School Day : My Family's Experience with Brain Injury
Brain Injury Association of Maryland, illus. by Debbie Kitchen
Washington, DC : Brain Injury Association, Inc. - 34p. : col. ill. 1995

# NOTES

# NOTES